



2018 IKCC PATIENT SURVEY -GLOBAL-

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Preface

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

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

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

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

¹ <https://www.perceptioninsight.ca>

Reader's Notes

There are three types of tables in this report:

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

1. Global Outlier Tables

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

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

'Average per patient' is calculated as the total number of responses divided by the total number of respondents. For example, in Table 3, patients Germany, on average, had a lack of understanding of 4 of the 6 aspects of disease related understanding. However, in Mexico, patients on average had lack of understanding for only 1 aspect.

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 the Global results, unless otherwise specified as either 'Global Outliers' or 'notable differences' to global results.

INTRODUCTION

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

Kidney cancer (renal cell carcinoma or RCC) is the seventh most common histological type of cancer in the Western world³ 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?

² www.ikcc.org

³ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4492569>

- Of those who were asked to participate, what sources of information about clinical trials had they been using?
- How well did patients understand the risks and benefits of enrolling?

Quality of Care

- To what extent were patients treated for their RCC, and where had they been receiving treatment?
- What specific physical and psychosocial issues had patients been 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- Global

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

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

- Advocate for the early and universal diagnosis of all RCC patients including females and younger patients who fall outside the typical patient demographic;
- Provide decision aid tools to enhance patient awareness and sub-type knowledge for newly diagnosed patients, thereby enabling them to best participate in shared decision making with their healthcare team about future treatment;
- Explore best practices to enhance patient understanding for various critical aspects of RCC upon initial diagnosis, as well as for treatment options available to patients;
- Explore communication practices of the healthcare community in countries such as France for enhancing patient understanding for various critical aspects of RCC upon initial diagnosis, as well as for treatment options available to patients. Along with France, Mexico was also more successful in providing newly diagnosed patients with not only an understanding about various aspects of RCC, but also for information about the possibility of patient participation in clinical trials. Both examples may provide the basis for exploring the possibility of best practices;
- 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 how kidney cancer has impacted their lives, and provide patients with the resources and tools for the psychological support they need. This is particularly relevant given evidence in this report suggesting that psychosocial issues may be worsening over time;
- Bring specific attention and focus to patient sub groups who may for whatever reason go unnoticed by the healthcare community, such as those with localised RCC, and those with no evidence of the disease or who have been told they were cured, and to their particular struggles so that they too might benefit from a better patient experience and overall quality of life;
- There may be an opportunity for IKCC to explore opportunities for best practices in Japan relative to both physical conditions and psychosocial issues, and with India due to its relative success in dealing with patients' psychosocial issues;
- There is also an opportunity for IKCC and its Affiliate Organisations to advocate for change and provide support for patients who struggle with barriers standing in the way of their right to quality care, including often overlooked patient sub groups;
- Specific sub-groups of patients such as German middle-aged patients (30-45 yrs.) and German patients with rarer sub-types were affected considerably less by barriers to quality care than patients in other countries, suggesting the potential to explore best practices. France is also notable, with the lowest number of barriers per patient compared to global results;

- Improve the survivorship of patients by empowering patients through education to advocate for regular surveillance despite gender, age or stage; and
- Advocate for shared decision making for patient treatment plans through further development of decision aid tools where there is evidence of physician directed care.

SURVEY RESULTS- Global

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 including:

| Country | Respondents | |
|---------------|-------------|-------------|
| | No. | % |
| Canada | 246 | 12 |
| France | 238 | 12 |
| United States | 233 | 12 |
| South Korea | 229 | 12 |
| Japan | 195 | 10 |
| UK | 181 | 9 |
| Mexico | 144 | 7 |
| India | 140 | 7 |
| Germany | 128 | 6 |
| Brazil | 51 | 3 |
| Netherlands | 46 | 2 |
| Australia | 38 | 2 |
| Finland | 31 | 2 |
| Other | 84 | 4 |
| TOTAL | 1983 | 100% |

Respondent Demographic Profile:

- 71% of those responding to the survey were kidney cancer patients while the remaining 29% defined themselves as a caregiver, family member or friend of the patient.
- 54% of respondents were males, 45% were females, and 1% did not self-identify, and
- Survey respondents had the following age profile:
 - Under 18 (1%),
 - 18-29 (2%),

- 30-45 (20%),
 - 46-65 (57%), and
 - 66+ (20%).
-
- Survey respondents were in the following stages of kidney cancer:
 - Localised kidney cancer (23%, compared to 60% in Mexico and 73% in India, both Global Outliers, and 6% in Germany),
 - Metastatic (44%, compared to 26% in Mexico and 17% in India, both Global Outliers, and 58% in the United States), and
 - No evidence/told they were cured (33%, compared to 48% in Germany, 10% in India and 14% in Mexico, all Global Outliers).

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 with the notable inclusion of females and younger patients.

It is imperative that patients 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.

There may be an opportunity for IKCC to explore best practices with France and Mexico for enhancing patient understanding for various critical aspects of RCC upon initial diagnosis, as well as for communicating treatment options available to patients.

38% of patients globally were not told their sub-type upon initial diagnosis, a foundational piece of information of which all RCC patients should be aware.

It is interesting to note that compared to global results, patients in:

- Germany were among those most aware of their sub-type but among the worst in understanding various aspects of their disease at initial diagnosis; and the least understanding of RCC treatments and guidelines at the time of the survey;***
- Mexico had among the worst awareness of their sub-type, but among the best understanding of their disease and care; and***

- *Those in France had the most understanding of various aspects of their disease upon diagnosis, as well as the greatest degree of understanding for treatment guidelines and care at the time of the survey.*

Globally, there was a notable difference between patients with clear cell RCC and those with rarer sub-types, for this understanding upon initial diagnosis.

Notable findings worthy of further investigation by IKCC and its Affiliates include the following:

- *At the time of the survey, 50% of patients in Germany had no understanding of biopsies for RCC, a diagnostic tool that is playing an increasing role in the diagnosis and treatment path for localised and metastatic patients;*
- *44% of patients in Germany had no understanding of radiation therapies, another key treatment used particularly for metastatic patients; and*
- *58% of those in Japan had no understanding of active surveillance, an emerging treatment option which enables the delay or elimination of surgical intervention, potentially mitigating the over-treatment of patients;*

Globally, females and younger patients took notably longer to be diagnosed with RCC compared to male patients and those in older age brackets.

Year of Diagnosis

- Patients who responded to this survey had been diagnosed in the following years:
 - 7% prior to 2005,
 - 2% in 2005
 - 2% in 2006,
 - 2% in 2007,
 - 3% in 2008,
 - 3% in 2009,
 - 4% in 2010,
 - 5% in 2011,
 - 6% in 2012,
 - 7% in 2013,
 - 8% in 2014,
 - 10% in 2015,
 - 13% in 2016,
 - 20% in 2017, and
 - 12% in 2018.

Success of Timely Diagnosis

- Globally, patients were in the following stages of their kidney cancer when they were first diagnosed:
 - 53% in Stages 1 or 2 (compared to 28% in Mexico, a Global Outlier and 64% in Japan),
 - 20% in Stage 3 (compared to 41% in India and 39% in Mexico, both Global Outliers, and 15% in Canada), and
 - 26% in Stage 4 (compared to 14% in Germany, a Global Outlier, and 34% in the United States).

- Following their first visit to the doctor, globally, 52% of patients were correctly diagnosed in less than a month (compared to 10% in Mexico, a Global Outlier and 67% in the United States), while
 - 26% were diagnosed in 1-3 months (compared to 54% in India, 16% in Mexico and 13% in the United States, all Global Outliers),
 - 10% in 3-6 months (compared to 23% in Mexico and 3% in South Korea, both Global Outliers),
 - 6% in 6 months to a year (compared to 26% in Mexico and 1% in South Korea, both Global Outliers), and

- 6% in more than one year (compared to 26% in Mexico and 11% in the UK, both Global Outliers and 0% in South Korea).
- Globally, 20% of patients were diagnosed at a family doctor or GP's office (compared to 0% in South Korea, a Global Outlier and 37% in Germany),
 - 12% at an emergency department (compared to 29% in the United States, a Global Outlier, 4% in India and Japan),
 - 37% at a community, local or general hospital (compared to 13% in the United States and 54% in both Japan and South Korea),
 - 13% at a major cancer centre⁴ (compared to 32% in Mexico and 3% in Germany),
 - 11% at a private clinic (compared to 26% in India and 21% in France, both Global Outliers, and 0% in Germany), and
 - 7% at some other facility (compared to 27% in Germany, a Global Outlier, and 0% in both India and Mexico).
- According to Table 1, globally, females took notably longer to be diagnosed than male patients, with 82% of male patients diagnosed in 3 months or less compared to 73% of females. There was no notable difference in the time of diagnosis between males and females in Germany, South Korea, Mexico or the United States, however females took notably longer to be diagnosed than males in Japan, France, Canada, the UK and India.

Table 1
Notable Global Differences for
Time of Diagnosis by Gender

| TIME OF DIAGNOSIS | Male | Female | Notable Differences |
|----------------------|------|--------|---------------------|
| Less than month | 55% | 48% | 7% |
| 1-3 months | 27% | 25% | |
| 3-6 months | 8% | 11% | |
| 6 months-1 year | 4% | 8% | |
| More than 1 year | 5% | 7% | 6% |
| LEGEND | | | |
| Most negative | | | |
| Most positive | | | |

⁴ Includes kidney cancer specialists at major cancer centres (8% compared to 19% in South Korea, 5% in France and 2% in Germany, all Global Outliers),

- As Table 2 shows, younger patients took notably longer to be diagnosed than older age groups with 52% of those under 30 yrs. diagnosed in 3 months or less compared to higher percentages for all other age groups.
- For the age groups reported, younger patients in Japan, Canada, the UK, the United States and France took longest to be diagnosed compared to older patients, while this was the case for older patients in Germany, Mexico and India. There was no notable difference in the time of diagnosis between different age groups in South Korea.

Table 2
Notable Global Differences for
Time of Diagnosis by Age

| TIME OF DIAGNOSIS | Under 30 yrs. | 30-45 yrs. | 46-65 yrs. | 66+ yrs. |
|--------------------------|----------------------|-------------------|-------------------|-----------------|
| Less than month | 25% | 43% | 55% | 55% |
| 1-3 months | 27% | 30% | 24% | 28% |
| 3-6 months | 23% | 12% | 10% | 7% |
| 6 months-1 year | 13% | 8% | 6% | 5% |
| More than 1 year | 13% | 8% | 6% | 5% |
| LEGEND | | | | |
| Most negative | | | | |
| Most positive | | | | |

Patient Knowledge and Understanding

- After initial diagnosis 38% of patients globally were not told their sub-type (compared to 61% in India and 54% in Mexico, 24% in Germany, and 22% in the United States, all Global Outliers).
- As shown in Table 3, at the time of diagnosis,
 - 20% had no understanding of their stage (compared to 68% in Germany, a Global Outlier, and 9% in France),
 - 43% had no understanding of their subtype⁵ (compared to 86% in Germany, 55% in the UK, 23% in Mexico and 20% in France, all Global Outliers),

⁵ For the purposes of analysis, sub-types have been categorized into 'clear cell RCC' and 'other' sub-types which include all other remaining sub-types reported by respondents

- 21% had no understanding of their treatment options (compared to 62% in Germany 31% in South Korea and 3% in France, all Global Outliers),
 - 19% had no understanding of their treatment recommendations (compared to 64% in Germany, 39% in India and 4% in France, all Global Outliers),
 - 28% had no understanding of the risk of recurrence (compared to 68% in Germany and 12% in France, both Global Outliers), and
 - 25% had no understanding of their likelihood of survival (compared to 63% in Germany, 35% in India and 14% in France and Mexico, all Global Outliers).
- Patients in Germany had the least understanding of any other country surveyed for various aspects of their disease and care (4.11 per patient), while French and Mexican patients had the best understanding for all aspects of their RCC (.62 and 1.03 respectively).

Table 3
Global Outliers for
Lack of Patient Understanding at Time of Diagnosis

| No Understanding | GLOBAL | France | Germany | India | Mexico | South Korea | UK |
|--------------------------|--------|--------|---------|-------|--------|-------------|-----|
| Stage | 20% | 9% | 68% | | | | |
| Sub-Type | 43% | 20% | 86% | | 23% | | 55% |
| Treatment Options | 21% | 3% | 62% | | | 31% | |
| Treatment Recommendation | 19% | 4% | 64% | 39% | | | |
| Risk of Recurrence | 28% | 12% | 68% | | | | |
| Likelihood of Survival | 25% | 14% | 63% | 35% | 14% | | |
| Average per patient | | .62 | 4.11 | | 1.03 | | |
| LEGEND | | | | | | | |
| Most negative | | | | | | | |
| Most positive | | | | | | | |

- Globally, when the percentage of patients with clear cell RCC is compared to the percentage of patients with other sub-types for knowledge and understanding, there is no notable difference except in the case where 27% of clear cell RCC patients had no understanding of the likelihood of their survival compared to 21% of those patients with other sub-types (as shown in Table 4, this represents a difference of 6%).
- As shown in Table 4, there is evidence to suggest that patients with clear cell RCC were at a notable disadvantage when it comes to understanding crucial aspects of their disease in India.

Table 4
Global Outliers for
Differences between Clear cell RCC and Other Sub-types for
Lack of Understanding at Time of Diagnosis⁶

| NO UNDERSTANDING of... | Global | Germany | India | South Korea | UK | United States |
|--|--------|---------|-------|-------------|-----|---------------|
| Stage | | 6% | | | 11% | |
| Sub-Type | | | 14% | | | 14% |
| Treatment Options | | | 17% | 6% | | |
| Treatment Recommendation | | 9% | 16% | | 5% | |
| Risk of Recurrence | | | | 13% | | 9% |
| Likelihood of Survival | 6% | | 12% | | | |
| LEGEND | | | | | | |
| Patients with Other Sub-types had less understanding than patients with clear cell | | | | | | |
| Patients with Clear Cell had less understanding than patients with other sub-types | | | | | | |

- At the time of the survey, 11% of patients were still not aware of their sub-type (compared to 32% in India and 2% in the United States, both Global Outliers).
- The 14% who were aware had the following RCC sub-types:
 - Clear cell (62%)
 - Papillary (6%),
 - Chromophobe (5%),
 - Unclassified (4%),
 - XP11 Translocation Type (1%),
 - VHL (2%),

⁶ Due to insufficient sample size, data is not reported for Mexico

- Renal Medullary (<1%),
 - Collecting Duct (1%),
 - Transitional Cell Carcinoma (<1%),
 - Renal Sarcoma (<1%),
 - Wilms Tumour (<1%),
 - Benign Tumour (1%),
 - Other (4%).
- Table 5 shows the Global Outliers for the lack of patient understanding about treatment and guidelines for RCC care. Patients had no understanding of the following:
 - Biopsies for kidney cancer (20%),
 - Surgical options (8%).
 - Immunotherapy (26%),
 - Targeted therapies (23%),
 - Radiation therapies (29%),
 - Ablative therapies (41%),
 - Palliative care (33%),
 - Active surveillance (29%),
 - Nutrition/lifestyle (14%),
 - Complementary therapies (39%),
 - Guidelines for kidney cancer care (20%), or for
 - Guidelines for kidney cancer follow-up (17%).
 - Patients in Germany and India overall had the worst understanding about the treatments and guidelines of their disease (4.3 per patient), while patients in France had the best understanding (1.6 per patient).
 - The lack of understanding of the guidelines for kidney cancer care was 20% globally (compared to 35% in the UK and 25% in Germany, both Global Outliers, and 15% in the United States).
 - The lack of understanding of the guidelines for kidney cancer follow up was 17% globally (compared to 32% in the UK, a Global Outlier, and 8% in France.)

Table 5
Global Outliers for
Lack of Understanding about Treatments and Guidelines

| NO UNDERSTANDING of... | Global | Canada | France | Germany | India | Japan | Mexico | UK | United States |
|--|--------|--------|--------|---------|-------|-------|--------|-----|---------------|
| Biopsies for kidney cancer | 20% | | 5% | 50% | | | | | |
| Surgical options | 8% | | 2% | | | | 24% | | |
| Immunotherapy | 26% | | 12% | | 61% | | | | 17% |
| Targeted therapies | 23% | | 14% | | 48% | | | | |
| Radiation therapies | 29% | | 12% | 44% | | | 19% | | |
| Ablative therapies | 41% | | | 68% | | 4% | | | |
| Palliative care | 33% | | | 55% | 52% | | 15% | | |
| Active surveillance | 29% | | 11% | 48% | | 58% | | | 15% |
| Nutrition/lifestyle | 14% | 12% | | | | | 23% | | 7% |
| Complementary/alternative therapies | 39% | | | | | 75% | 21% | | |
| Guidelines for kidney cancer care | 20% | | | 25% | | | | 35% | 15% |
| Guidelines for kidney cancer follow up | 17% | | 8% | | | | | 32% | |
| Average per patient | | | 1.6 | 4.3 | | | | | |
| LEGEND | | | | | | | | | |
| Most negative | | | | | | | | | |
| Most positive | | | | | | | | | |

III. Clinical Trials

Every kidney cancer patient 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 is a high degree of willingness amongst patients in every country 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 through major cancer centres by providing them with the necessary information at crucial stages of their treatment pathway that would both motivate them and make them feel comfortable in advocating for their own treatment decisions.

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

With 70% of patients never having been asked to participate in a clinical trial, there is evidence to suggest that the global healthcare community has not been proactive in approaching RCC patients about their possible participation.

The fact that 89% of patients who had never been approached to participate in a clinical trial reported they would be fairly likely to do so if asked, particularly if provided with the necessary information to make the decision. The high rate of participation and degree of satisfaction with the experience of those who were asked indicates an obvious lost opportunity to improve the quality of care and survivorship of RCC patients through research. Globally, nearly half of patients who had never been asked to participate in a clinical trial were being treated at major cancer centres.

The majority of patients had the option of a clinical trial discussed with them after surgery or other treatments rather than initial diagnosis. There is an opportunity to make patients more aware of the risks and benefits of participating at an earlier point, to ensure a greater likelihood of participation.

Notable findings worthy of further investigation by the IKCC include the following:

- Patients in Germany had the most reasons per patient why they were not willing to participate in a clinical trial and, notably, a considerable distrust of clinical trials compared to patients in other countries;*
- In contrast, there is a particularly notable missed opportunity in Japan, where 91% of patients had never been asked to participate in a clinical trial. Yet they reported the fewest reasons per patient for not wanting to participate as well as the highest likelihood of participation should they be asked.*

Patients who HAD DISCUSSIONS about clinical trials

- According to survey results, clinical trials had not been discussed with 33% of patients globally (compared to 52% in the UK, and 13% in South Korea)
- Of those who had discussions about clinical trials, those discussions had occurred globally with:
 - Another patient (12% compared to 22% in the United States, and 6% in Japan, both Global Outliers),
 - Doctors (75% compared to 43% in Mexico, a Global Outlier, and 94% in India),
 - Spouses, friends or family (31% compared to 52% in South Korea, 51% in Japan, both Global Outliers, and 11% in Germany),
 - Nurses (10% compared to 22% in the UK, a Global Outlier, and 3% in Germany),
 - Patient organisations (19% compared to 40% in South Korea, 36% in Germany, 10% in Mexico and 8% in France, all Global Outliers), and
 - Online groups (15% compared to 40% in the United States, 27% in the UK, 4% in France, and 1% in India, all Global Outliers).

Patients who HAD NEVER BEEN ASKED to participate in a clinical trial⁷

- 70% of patients globally had never been asked to participate in a clinical trial (compared to 59% in France and 91% in Japan).
- Of the 70% of patients who had never been asked to participate in a clinical trial, 89% said it 'fairly likely'⁸ they would do so if asked (compared to 98% in the UK, 97% in South Korea, and 79% in Mexico, all Global Outliers).
- Of the patients who said they would be fairly likely⁹ to do so, they were being treated¹⁰ at:
 - Community/ local /general hospitals (37% globally, compared to 57% in Japan and 52% in the UK, both Global Outliers, and 27% in the United States),

⁷ Due to insufficient data, results are not reported for India.

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

⁹ 'Fairly likely' is the combined result of 'Likely' and 'Maybe; would need more information'. Due to insufficient sample sizes, data is not reported for India.

¹⁰ Due to insufficient sample size, data is not reported for India.

- Major cancer centres¹¹ (45%),
 - 6% at private clinics (compared to 14% in France and 0% in Germany and South Korea), and
 - 5% at 'other' (compared to 36% in Germany, a Global Outlier, and 0% in Mexico and South Korea).
- Of the 89% of patients who said it would be 'fairly likely' they would participate in a clinical trial¹²:
 - 38% said they would be 'likely' to participate (compared to 28% in the United States, 29% in Mexico, both Global Outliers, and 44% in Canada), while
 - 62% 'would require more information to make a decision of whether or not to do so' (compared to 72% in the United States, 71% in Mexico, both Global Outliers, and 56% in Canada).
- Of the patients who said they would need more information before they agreed to participate in a clinical trial, these patients were being treated¹³ at:
 - Community/ local /general hospitals (38% globally, compared to 59% in Japan, a Global Outlier, and 26% in the United States),
 - Major cancer centres¹⁴ (44% globally, compared to 34% in Japan and the UK and 63% in South Korea),
 - 7% at private clinics (18% in the United States, a Global Outlier and 0% in Japan and South Korea), and
 - 6% at 'other' (compared to 5% in Canada, and 0% in Mexico and South Korea).

¹¹ Includes kidney cancer specialists at major cancer centres (30% compared to 60% in South Korea, a Global Outlier, and 17% in Germany)

¹² Due to insufficient sample size, data is not reported for India.

¹³ Due to insufficient sample size, data is not reported for India or Germany.

¹⁴ Includes kidney cancer specialists at major cancer centres (30% globally, compared to 59% in South Korea and 19% in the UK ,both Global Outliers),

- Patients who would be fairly likely to participate in a clinical trial, if asked, consisted of:
 - 87% of patients with localised RCC (compared to 97% in South Korea¹⁵ and 78% in India),
 - 92% of those with metastatic RCC (compared to 79% in Mexico¹⁶, a Global Outlier, and 100% in Canada), and
 - 91% of those with no evidence of the disease or were told they were cured (compared to 98% in the UK¹⁷, a Global Outlier, and 87% in Canada).

- As shown in Table 6, globally, 10% more patients with other sub-types had never been asked to participate in a clinical trial (compared to 20% in Canada, a Global Outlier).

Table 6
Notable Differences between Clear Cell and Other Sub-Types of RCC¹⁸ for Patients who had never been asked to Participate in a Clinical Trial

| | Clear Cell | Other Sub-type | Notable Differences |
|---|-------------------|-----------------------|----------------------------|
| Global | 67% | 77% | 10% |
| Canada | 54% | 74% | 20% |
| France | 59% | 66% | 7% |
| Germany | 80% | 91% | 11% |
| India | 70% | 50% | 20% |
| Japan | 89% | 97% | 8% |
| South Korea | 59% | 69% | 10% |
| UK | 69% | 76% | 7% |
| United States | 58% | 69% | 11% |
| LEGEND | | | |
| More patients with clear cell had not been asked | | | |
| More patients with other sub-types had not been asked | | | |

¹⁵ Due to insufficient data, results are not reported for Germany or the UK.

¹⁶ Due to insufficient data, results are not reported for India.

¹⁷ Due to insufficient data, results are not reported for India or Mexico.

¹⁸ Due to insufficient data, results are not reported for Mexico

- Globally, patients being treated for other sub-types who had never been approached to participate in a clinical trial were being treated¹⁹ at:
 - Community/local or general hospitals (28% globally compared to 64% in Japan, 54% in the UK, and 7% in Germany, all Global Outliers),
 - Major cancer centres²⁰ (47% compared to 78% in South Korea and 22% in Japan),
 - Private clinics (9% globally, compared to 21% in Mexico, 13% in the United States, both Global Outliers and 0% in Japan, South Korea and Germany), and at
 - Other (9% compared to 34% in Germany and 28% in Canada, both Global Outliers and 0% in Mexico and South Korea).

Patients who HAD BEEN ASKED to participate in a clinical trial

- Of the patients who were asked to participate in a clinical trial:
 - 9% of their initial discussions were with another patient (compared to 23% in the United States and 0% in both Japan and Mexico, all Global Outliers),
 - 88% with doctors (compared to 67% in Mexico, a Global Outlier, and 97% in India),
 - 31% with spouses, family or friends (compared to 56% in South Korea, and 50% in Japan, both Global Outliers and 3% in India),
 - 15% with nurses (compared to 33% in Mexico, a Global Outlier and 0% in Germany),
 - 18% with patient organisations (compared to 49% in South Korea a Global Outlier and 6% in India),
 - 16% with online groups (compared to 35% in the United States and 26% in the UK, both Global Outliers and 0% in both India and Mexico),
 - 2% had not discussed it with anyone (compared to 8% in Mexico, a Global Outlier and 0% in Germany, India and South Korea), and
 - 1% with 'other' (compared to 15% in Germany, a Global Outlier and 0% in India, Japan, Mexico, the UK and the United States).

¹⁹ Due to insufficient sample size, data is not reported for India.

²⁰ Includes major cancer centres with kidney cancer specialists (30% globally compared to 68% in South Korea, a Global Outlier, and 18% in Japan)

- The option of a clinical trial had first been discussed with:
 - 24% upon diagnosis (compared to 48% in India and 8% in France, both Global Outliers),
 - 49% of patients after surgery (compared to 63% in Germany, 59% in the UK and 25% in Mexico, all Global Outliers),
 - 21% after other treatments (compared to 42% in France, 3% in India and 4% in the UK, all Global Outliers), and
 - 6% who were left with no other treatment options (compared to 12% in South Korea and 0% in Germany, India and Japan).

- For patients who had the option of a clinical trial first discussed with them after surgery²¹:
 - 18% were being treated at community/local or general hospitals (compared to 36% in Germany, and 5% in France, both Global Outliers),
 - 72% at major cancer centres²² (compared to 84% in France and the United States and 36% in Germany), and
 - 3% at private clinics (compared to 33% in India, a Global Outlier, and 0% in Canada, France, Germany, South Korea and the UK).

- When the option of a clinical trial was discussed with patients:
 - 47% understood very well the risks and benefits of participating (compared to 64% in France, and 62% in the UK, both Global Outliers, and 17% in Mexico),
 - 41% had at least some understanding (compared to 76% in India, a Global Outlier, and 30% in both France and the UK), and
 - 12% had a very limited understanding (compared to 42% in Germany, a Global Outlier, and 3% in India).

- Of those who were asked to participate in a clinical trial²³, 86% had agreed (compared to 100% in Japan and 74% in Germany, both Global Outliers).

²¹ Due to insufficient sample sizes, data is not reported for Japan or Mexico.

²² Includes major cancer centres without kidney specialists (57% compared to 27% in Germany and 13% in India, both Global Outliers, and 70% in the UK)

²³ Due to insufficient sample size, data is not reported for Mexico.

- Those who had agreed to participate did so because²⁴:
 - Their doctor recommended it (55% globally compared to 73% in Canada and 19% in India, both Global Outliers),
 - They thought it might offer better care (61% globally compared to 23% in India and 15% in Germany, both Global Outliers, and 79% in Japan and South Korea),
 - They wanted a specific type of treatment (13% globally compared to 23% in Germany, and 5% in the UK),
 - It was their only option for treatment (22% globally compared to 58% in India and 5% in the UK, both Global Outliers),
 - They wanted to help kidney cancer research (39% globally compared to 4% in South Korea and 3% in India, both Global Outliers and 62% in Germany), and
 - Affordability, financial reasons (13% globally compared to 50% in Japan, a Global Outlier and 0% in France, Germany and the UK).

- Globally, 90% of patients who participated in a clinical trial were either 'very satisfied' or 'satisfied' and of those²⁵:
 - 44% were very satisfied (compared to 64% in the UK, and 23% in both India and South Korea),
 - 46% were satisfied (compared to 73% in India and 33% in Canada, the UK and the United States), and
 - 10% were very dissatisfied (compared to 17% in France, a Global Outlier, and 3% in India and the UK).

- Table 7 illustrates reasons for the unwillingness of patients who either had either never been asked to participate in a clinical trial or who had declined their participation.

- Patients in Germany had the greatest number of reasons for which they were not willing to participate in a clinical trial (2.75 per patient), compared to 1.18 in Japan.

²⁴ Due to insufficient sample size, data is not reported for Mexico.

²⁵ Due to insufficient sample size, data is not reported for Germany or Mexico

Table 7
Global Outliers for
Reasons for Lack of Participation in Clinical Trials²⁶

| REASON | GLOBAL | Canada | France | Germany | India | Japan | Mexico | South Korea | United States |
|---------------------------------------|--------|--------|--------|---------|-------|-------|--------|-------------|---------------|
| Lack of information | 19% | | | 31% | 7% | | | | 31% |
| Not eligible | 21% | | 33% | | 7% | | | 36% | |
| Distrust of trials | 21% | 7% | | 44% | | | | | |
| Fear of placebo | 18% | | 33% | | | 0% | | | |
| Fear of uncertainty | 26% | 17% | 22% | | 36% | | | 36% | |
| Extra tests or interventions required | 18% | | 0% | 31% | | | | | |
| Geographic distance | 16% | | | 44% | | 0% | | 0% | |
| Affordability | 7% | | 0% | 0% | | 0% | 19% | | |
| Not available | 14% | | 0% | 25% | | | 30% | | |
| Toxicity of treatment | 22% | 14% | | | | 9% | 33% | | |
| Other | 16% | 31% | | | | 0% | | | |
| Average no. of reasons per patient | | | | 2.75 | | 1.18 | | | |
| LEGEND | | | | | | | | | |
| Most negative | | | | | | | | | |
| Most positive | | | | | | | | | |

²⁶ Due to insufficient data, results are not reported for the UK.

IV. Quality of Care

Kidney cancer has a profound effect on the lives of patients globally 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 everywhere 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 particularly for anxiety related issues. This is particularly relevant given evidence suggesting that psychosocial issues 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 under-served but heavily impacted patient sub groups such as patients with localised RCC, and those with no evidence of the disease or who have been told they were cured, thereby ensuring universal psychological support for all patients.

There may be an opportunity for IKCC to explore opportunities for best practices in Japan related to both physical conditions and psychosocial issues, and in India in dealing with patients' psychosocial issues.

There is a role for IKCC and its Affiliate Organisations to advocate for change and provide support for patients who struggle with barriers to quality care. It is noteworthy that German middle aged patients (30-45 yrs.) and those with rarer sub-types experienced considerably fewer barriers than patients in other countries, suggesting the potential to explore best practices. France is also notable, with the lowest number of barriers per patient compared to global results.

92% of patients globally were affected by physical conditions, fatigue being the most impactful by a considerable margin over other reported conditions. There were considerable differences between patients in different countries for the degree to which they were affected. For example, patients in Japan reported the lowest number of physical

conditions per patient, suggesting an opportunity for IKCC to visit best practices, while those in the UK were impacted by the highest number of physical conditions per patient.

96% of patients globally were affected by psychosocial issues and 'difficult times'. Issues related to anxiety were most prevalent, including for example, disease related anxiety, the fear of recurrence, the fear of dying, general anxiety, the process of diagnosis and waiting for surgery or scan results. There is evidence to suggest that many of the psychosocial issues that patients faced may have become more prevalent for those patients diagnosed since 2014.

Results by stage are of notable interest. Surprisingly, despite the fact that the majority of patients with localised RCC are not on any drug treatment, they were still affected by a number of physical conditions, most notably fatigue, muscle weakness and sleeplessness. Similarly, patients with no evidence of the disease or who had been told they were cured were also impacted by several physical conditions of which fatigue, pain related to surgery and sleeplessness were the most impactful.

Compared to global results, patients in the United States were impacted by the greatest number of psychosocial issues and 'difficult times' per patient, while those in India and Japan were affected the least.

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

Despite the fact that 96% of patients were impacted by psychosocial issues and a very high percentage were finding their doctors to be helpful when they did reach out, only half communicated their issues to a healthcare professional. A higher proportion of younger patients and females chose not to communicate the full extent of their emotional issues to their healthcare team.

Compared to global results, patients in Mexico experienced the greatest number of barriers per patient to receiving quality care. This is in contrast to patients in France who reported the lowest number per patient.

Globally, younger patients, an age group not necessarily representative of the demographic of a typical RCC patient, were affected more notably by barriers to receiving quality care than older age groups. Patients in older age brackets in Mexico, India and South Korea were considerably more affected by barriers to receiving quality care compared to patients in other countries.

Patients with rarer sub-types were affected overall by notably more barriers to receiving quality care than patients with clear cell RCC. Patients in Germany with rarer sub-types and those aged 40-65 yrs. were unique in that they experienced the fewest number of barriers per patient compared to patients globally: a call to explore best practices.

Patients in India and South Korea experienced lack of affordability and cost of treatment to a greater degree than patients in other countries. These were also the largest barriers facing patients, related directly to the healthcare systems in each of those countries.

- According to survey results, 4% of patients globally had not had any treatment for their kidney cancer after first diagnosis (compared to 10% in Canada and France, both Global Outliers, and 0% in Japan and South Korea, all Global Outliers).
- Globally, at the time of the survey, 7% of patients were not being treated at all (compared to 11% in Canada and France, both Global Outliers, and 1% in India).
- As shown in Table 8, for their first treatment,
 - 47% had received them from community centres/local or general hospitals (compared to 69% in Germany, and 26% in India),
 - 38% at major cancer centres²⁷ (compared to 61% in India and 24% in Germany), and
 - 7% from private clinics (compared to 21% in France and 19% in Mexico, both Global Outliers, and 0% in Germany).
- Of those patients who had been receiving treatments since that time:
 - 31% had been receiving them from community/local or general hospitals (compared to 59% in Japan and 42% in the UK, both Global Outliers and from 18% in the United States),
 - 51% from major cancer centres²⁸ (compared to 70% in South Korea and 27% in Germany),
 - 7% from private clinics (compared to 19% in Mexico and 18% in India, both Global Outliers, and 0% in Germany and South Korea), and
 - 4% from 'other' (compared to 33% in Germany and 8% in Canada, both Global Outliers and 0% in Mexico, India and South Korea).

²⁷ Includes 26% from major cancer centres by doctors specialising in kidney cancer (compared to 50% in South Korea, 16% in Mexico and 15% in Germany, all Global Outliers),

²⁸ Includes 36% from major cancer centres by doctors specialising in kidney cancer (compared to 63% in South Korea, a Global Outlier and 17% in Mexico).

- As can be seen in Table 8, 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 16% in community centres/local/general hospital treatments and an increase of 13% to major cancer centres.

Table 8
Notable Global Differences between Place of Treatment for Patient Initial and Subsequent Treatments

| PLACE OF TREATMENT | First Treatment | Subsequent Treatments | Notable Differences |
|-----------------------------------|-----------------|-----------------------|---------------------|
| No treatment/not being treated | 4% | 7% | |
| Community/local/general hospitals | 47% | 31% | -16% |
| Major cancer centres | 38% | 51% | 13% |
| Private clinics | 7% | 7% | |

Physical Conditions

- As can be seen in Table 9, globally, 8% of patients were not impacted by any conditions affecting their physical well-being since initial diagnosis.
- Of those who were impacted, fatigue was the physical condition affecting them the most (66% globally compared to 78% in the UK, and 18% in Mexico, both Global Outliers).
- Patients in the UK had the most physical conditions with an average number of 5.91 conditions per patient, compared to 3.2 in Japan.

**Table 9
Global Outliers for
Physical Conditions**

| PHYSICAL CONDITION | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|---------------------------------------|---------------|---------------|---------------|----------------|--------------|--------------|---------------|--------------------|-----------------------|----------------------|
| NOT AFFECTED | 8% | 13% | | 14% | 2% | | 2% | | | |
| Fatigue | 66% | | | | | | 18% | | 78% | |
| Trouble concentrating | 24% | | | | | 13% | | | 34% | |
| Mucositis/mouth ulcers | 17% | | | | 40% | 7% | | | | |
| Muscle weakness | 32% | 26% | | | 56% | 19% | | | | |
| Pain related to surgery | 29% | | | 22% | 22% | 36% | | | | |
| Bowel changes | 33% | | | | 11% | | | | 43% | 43% |
| Loss of appetite | 25% | | | | | 11% | 34% | | | |
| Changes in taste and smell | 25% | | | | | | | 19% | 31% | 34% |
| Sleeplessness | 31% | | | | | 22% | | 26% | 43% | |
| Itching | 17% | | 12% | | | 6% | 25% | | | |
| Hair loss | 13% | 7% | | | | | 26% | | | |
| Change of hair colour | 17% | | | | | 11% | | | 24% | 25% |
| Memory loss | 13% | | | | | 1% | 24% | | 21% | |
| Changes in sexual function | 15% | | | | 2% | 2% | 25% | | | |
| Aching joints | 22% | | | | | 6% | | | 36% | |
| Sore feet and hands | 23% | | | | 30% | | | 18% | | |
| Weight loss | 24% | | | | 31% | 12% | | 31% | 16% | |
| Cramps | 11% | | 19% | | | 1% | | 3% | | |
| Fluid retention | 12% | | | | | 5% | 23% | 2% | | |
| Skin reactions | 17% | 11% | | | 31% | | 28% | | | |
| Nausea and vomiting | 22% | | | | | 8% | 48% | | | |
| Average no. of conditions per patient | | | | | | 3.2 | | | 5.91 | |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- As shown in Table 10, there were notable differences in how males and females were impacted by physical conditions.

- Males were affected more by:
 - Changes in taste and smell,
 - Changes in sexual function,
 - Weight loss, and by
 - Skin reactions.

- Females were affected more by:
 - Trouble concentrating,
 - Pain related to surgery, and by
 - Hair loss.

Table 10
Notable Differences for
Physical Conditions by Gender

| PHYSICAL CONDITION | Males | Females | Notable Difference |
|----------------------------|-------|---------|--------------------|
| NOT AFFECTED | 7% | 9% | |
| Fatigue | 66% | 66% | |
| Trouble concentrating | 20% | 28% | 8% |
| Mucositis/mouth ulcers | 18% | 15% | |
| Muscle weakness | 33% | 30% | |
| Pain related to surgery | 26% | 32% | 6% |
| Bowel changes | 34% | 31% | |
| Loss of appetite | 27% | 23% | |
| Changes in taste and smell | 28% | 22% | 6% |
| Sleeplessness | 30% | 34% | |
| Itching | 18% | 16% | |
| Hair loss | 9% | 17% | 8% |
| Change of hair colour | 19% | 16% | |
| Memory loss | 11% | 14% | |
| Changes in sexual function | 18% | 11% | 7% |
| Aching joints | 21% | 25% | |
| Sore feet and hands | 24% | 22% | |
| Weight loss | 27% | 20% | 7% |
| Cramps | 12% | 11% | |
| Fluid retention | 10% | 14% | |
| Skin reactions | 20% | 15% | 5% |
| Nausea and vomiting | 22% | 23% | |
| LEGEND | | | |
| Most negative | | | |
| Most positive | | | |

- As shown in Table 11, male patients in the UK and the United States were impacted by the greatest number of physical conditions with 5.95 and 6.32 respectively per patient, compared to 3.23 in Japan.

Table 11
Global Outliers for
Physical Conditions Affecting Males

| PHYSICAL CONDITION | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | UK | United States |
|---------------------------------------|--------|--------|--------|---------|-------|-------|--------|-------------|------|---------------|
| NOT AFFECTED | 7% | | | 14% | | | 2% | | | |
| Fatigue | 66% | | | | | | 25% | | | 83% |
| Trouble concentrating | 20% | | | | | 11% | | 16% | 28% | 28% |
| Mucositis/mouth ulcers | 18% | | | | 36% | 9% | | | | |
| Muscle weakness | 33% | | | | 53% | 17% | | | 25% | |
| Pain related to surgery | 26% | | | 16% | | 38% | | | 32% | |
| Bowel changes | 34% | | | | 6% | | | | 50% | |
| Loss of appetite | 27% | | | | | 12% | | | | 40% |
| Changes in taste and smell | 28% | | | | | | 11% | | | 42% |
| Sleeplessness | 30% | | | | 41% | 20% | | | | |
| Itching | 18% | | | | | 8% | | | 28% | |
| Hair loss | 9% | 5% | 5% | | | | 25% | | | |
| Change of hair colour | 19% | | | | | 10% | | | 25% | 32% |
| Memory loss | 11% | | | | | 0% | 24% | | | |
| Changes in sexual function | 18% | | | | 1% | | | | | 34% |
| Aching joints | 21% | | | | | 7% | | | | 32% |
| Sore feet and hands | 24% | | | | | | 21% | 21% | 33% | |
| Weight loss | 27% | | | | 37% | 11% | | | 18% | |
| Cramps | 12% | 17% | 19% | | | 2% | | 3% | | |
| Fluid retention | 10% | | | 20% | | 2% | 24% | 2% | | |
| Skin reactions | 20% | | | | 33% | 13% | | 26% | | |
| Nausea and vomiting | 22% | | | | | 10% | 48% | | 36% | |
| Average no. of conditions per patient | | | | | | 3.23 | | | 5.95 | 6.32 |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- As can be seen in Table 12 female patients in Mexico and the UK reported the greatest number of physical conditions, with 6.14 and 5.87 per patient respectively, compared to 3.16 in Japan.

Table 12
Global Outliers for
Physical Conditions Affecting Females

| PHYSICAL CONDITION | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | UK | United States |
|---------------------------------------|--------|--------|--------|---------|-------|-------|--------|-------------|------|---------------|
| NOT AFFECTED | 9% | 21% | | | 0% | | 0% | | | |
| Fatigue | 66% | | | | | | 8% | | 83% | |
| Trouble concentrating | 28% | | | 44% | | | | 12% | 40% | |
| Mucositis/mouth ulcers | 15% | 5% | | | 44% | 5% | 31% | | | |
| Muscle weakness | 30% | 17% | | | 63% | 21% | | | | |
| Pain related to surgery | 32% | | | | 17% | | 47% | | | |
| Bowel changes | 31% | | | | 15% | 20% | | | | 41% |
| Loss of appetite | 23% | | | | | 10% | 37% | 34% | | |
| Changes in taste and smell | 22% | 11% | | | | | 34% | | | |
| Sleeplessness | 34% | 23% | | | | | | | 48% | |
| Itching | 16% | | 15% | | | 5% | 27% | | 20% | |
| Hair loss | 17% | 10% | | | | | 27% | 10% | | 27% |
| Change of hair colour | 16% | 7% | | | | | | | 24% | |
| Memory loss | 14% | | | | 4% | 2% | 24% | | 25% | |
| Changes in sexual function | 11% | | 20% | | | 1% | 24% | | | |
| Aching joints | 25% | | | | | 6% | | | 40% | |
| Sore feet and hands | 22% | | | | 31% | | 41% | 12% | | |
| Weight loss | 20% | | | | | 12% | 31% | | 14% | |
| Cramps | 11% | | 19% | | | 0% | 19% | 3% | | |
| Fluid retention | 14% | 20% | | | | | 22% | 3% | | |
| Skin reactions | 15% | 8% | | | 31% | | 36% | | | |
| Nausea and vomiting | 23% | | | | 38% | 6% | 49% | | | |
| Average no. of conditions per patient | | | | | | 3.16 | 6.14 | | 5.87 | |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- As the global percentages in Table 13 illustrates, there were notable differences in physical impact depending on the patient's year of diagnosis.
- Patients diagnosed in 2014 and later seem to have been impacted notably less than patients diagnosed prior to 2014 by:
 - Bowel changes,
 - Changes in sexual function,
 - Cramps, and by
 - Fluid retention.

Table 13
Notable Differences for
Physical Conditions by Year of Diagnosis

| PHYSICAL CONDITION | Prior to 2014 | 2014 and Later | Notable Difference |
|----------------------------|---------------|----------------|--------------------|
| NOT AFFECTED | 10% | 6% | |
| Fatigue | 65% | 67% | |
| Trouble concentrating | 24% | 24% | |
| Mucositis/mouth ulcers | 18% | 16% | |
| Muscle weakness | 29% | 33% | |
| Pain related to surgery | 26% | 30% | |
| Bowel changes | 38% | 30% | 8% |
| Loss of appetite | 25% | 26% | |
| Changes in taste and smell | 27% | 24% | |
| Sleeplessness | 29% | 33% | |
| Itching | 17% | 17% | |
| Hair loss | 15% | 12% | |
| Change of hair colour | 19% | 16% | |
| Memory loss | 14% | 12% | |
| Changes in sexual function | 21% | 12% | 9% |
| Aching joints | 23% | 22% | |
| Sore feet and hands | 25% | 22% | |
| Weight loss | 24% | 23% | |
| Cramps | 15% | 9% | 6% |
| Fluid retention | 15% | 10% | 5% |
| Skin reactions | 19% | 16% | |
| Nausea and vomiting | 25% | 21% | |
| LEGEND | | | |
| Most negative | | | |
| Most positive | | | |

- As shown in Table 14, patients in the UK diagnosed prior to 2014 reported the greatest number of physical conditions with 6.86 per patient, compared to 3.02 in Japan and 4.15 in Canada.

Table 14
Physical Conditions of Patients Diagnosed Prior to 2014

| PHYSICAL CONDITON | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|---------------------------------------|--------|--------|--------|---------|-------|-------|--------|-------------|----------------|---------------|
| NOT AFFECTED | 10% | 19% | 10% | 15% | N/A | | 0% | 6% | | |
| Fatigue | 65% | | | | N/A | | 16% | | 76% | |
| Trouble concentrating | 24% | | | | N/A | 10% | 10% | | 47% | |
| Mucositis/mouth ulcers | 18% | | | 24% | N/A | 10% | | | 24% | |
| Muscle weakness | 29% | 22% | | | N/A | 20% | | | 41% | |
| Pain related to surgery | 26% | | | 19% | N/A | 34% | 48% | | | |
| Bowel changes | 38% | | | | N/A | | 22% | | 53% | |
| Loss of appetite | 25% | 15% | | | N/A | 15% | | 37% | | |
| Changes in taste and smell | 27% | 18% | | | N/A | | | | 34% | |
| Sleeplessness | 29% | | | | N/A | 20% | | | 39% | |
| Itching | 17% | | | | N/A | 5% | | | 29% | |
| Hair loss | 15% | | | | N/A | 2% | 36% | | | |
| Change of hair colour | 19% | 11% | | | N/A | | | | 32% | |
| Memory loss | 14% | | | | N/A | 0% | | | 27% | |
| Changes in sexual function | 21% | 15% | | | N/A | 5% | 36% | | | |
| Aching joints | 23% | | | | N/A | 2% | 38% | | | 38% |
| Sore feet and hands | 25% | 18% | | | N/A | | 30% | | 34% | |
| Weight loss | 24% | 15% | | | N/A | | | 37% | | |
| Cramps | 15% | | 22% | | N/A | 0% | | | 22% | |
| Fluid retention | 15% | | | | N/A | 2% | 28% | | | |
| Skin reactions | 19% | | | | N/A | 7% | 36% | | | |
| Nausea and vomiting | 25% | | | | N/A | 5% | 42% | | | |
| Average no. of conditions per patient | | 4.15 | | | N/A | 3.02 | | | 6.86 | |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- Table 15 shows that patients in the United States diagnosed in 2014 and later reported the greatest number of physical conditions with an average of 5.62 per patient, compared to 3.25 in Japan and 4.36 in South Korea.

Table 15
Global Outliers for
Physical Conditions of Patients Diagnosed 2014 and Later

| PHYSICAL CONDTION | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|---------------------------------------|--------|--------|--------|---------|-------|-------|--------|-------------|----------------|---------------|
| NOT AFFECTED | 6% | 8% | 1% | N/A | | | | | | 7% |
| Fatigue | 67% | | | N/A | | | 18% | | 78% | 78% |
| Trouble concentrating | 24% | | | N/A | | 15% | | 14% | | 30% |
| Mucositis/mouth ulcers | 16% | | | N/A | 36% | 6% | | | | |
| Muscle weakness | 33% | | | N/A | 57% | 18% | | | 23% | |
| Pain related to surgery | 30% | | | N/A | 20% | | | | 39% | |
| Bowel changes | 30% | | | N/A | 6% | | | | | 43% |
| Loss of appetite | 26% | | | N/A | | 10% | 33% | | | 33% |
| Changes in taste and smell | 24% | | | N/A | | | 17% | | | 36% |
| Sleeplessness | 33% | | | N/A | | 23% | | 25% | 45% | |
| Itching | 17% | | 12% | N/A | | 7% | 28% | | | |
| Hair loss | 12% | 8% | | N/A | | | 20% | | 7% | |
| Change of hair colour | 16% | | | N/A | | 10% | | | | 23% |
| Memory loss | 12% | | | N/A | | 2% | 24% | | | |
| Changes in sexual function | 12% | | 18% | N/A | 1% | | 18% | | | 18% |
| Aching joints | 22% | | | N/A | | 8% | | 13% | 35% | 34% |
| Sore feet and hands | 22% | | | N/A | 31% | | | 17% | | |
| Weight loss | 23% | | | N/A | 35% | 10% | | | | |
| Cramps | 9% | | | N/A | | 2% | 21% | 2% | | |
| Fluid retention | 10% | | | N/A | | | 20% | 1% | | |
| Skin reactions | 16% | | | N/A | 27% | | | | 8% | |
| Nausea and vomiting | 21% | | | N/A | | 9% | 53% | | | |
| Average no. of conditions per patient | | | | N/A | | 3.25 | | 4.36 | | 5.62 |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- Table 16 shows that patients with localised RCC in Mexico had the greatest number of physical conditions with an average of 5.49 per patient, compared to 2.58 in Japan.

Table 16
Global Outliers for
Physical Conditions of Patients with Localised RCC

| PHYSICAL CONDITON | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | UK | United States |
|---------------------------------------|--------|--------|--------|---------|-------|-------|--------|-------------|-----|---------------|
| NOT AFFECTED | 6% | | | N/A | 0% | | | | N/A | 29% |
| Fatigue | 56% | | | N/A | | | 18% | 81% | N/A | |
| Trouble concentrating | 19% | | | N/A | 25% | 14% | | | N/A | 14% |
| Mucositis/mouth ulcers | 16% | | | N/A | 39% | | | 0% | N/A | 0% |
| Muscle weakness | 31% | | | N/A | 61% | 14% | | | N/A | 14% |
| Pain related to surgery | 28% | | | N/A | 14% | 47% | | | N/A | |
| Bowel changes | 20% | | 29% | N/A | | 11% | | | N/A | |
| Loss of appetite | 22% | | | N/A | | 11% | 33% | | N/A | |
| Changes in taste and smell | 19% | | 26% | N/A | | | | | N/A | 7% |
| Sleeplessness | 29% | 36% | 23% | N/A | | | | 23% | N/A | 36% |
| Itching | 15% | | | N/A | | 0% | 26% | | N/A | |
| Hair loss | 11% | 0% | | N/A | | | 22% | | N/A | 0% |
| Change of hair colour | 10% | 0% | | N/A | 19% | | | | N/A | |
| Memory loss | 10% | | | N/A | | 0% | 25% | | N/A | 0% |
| Changes in sexual function | 12% | | | N/A | | 0% | 29% | | N/A | |
| Aching joints | 18% | | 6% | N/A | | | 28% | | N/A | |
| Sore feet and hands | 17% | | | N/A | | | 29% | 7% | N/A | 7% |
| Weight loss | 22% | 32% | | N/A | | 14% | | | N/A | 14% |
| Cramps | 11% | 20% | | N/A | | 0% | | | N/A | 0% |
| Fluid retention | 12% | | | N/A | | | 22% | 2% | N/A | |
| Skin reactions | 18% | | | N/A | 33% | | | 2% | N/A | |
| Nausea and vomiting | 22% | | | N/A | 33% | 3% | 44% | | N/A | |
| Average no. of conditions per patient | | | | N/A | | 2.58 | 5.49 | | N/A | |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- Table 17 shows that patients with metastatic RCC in the United States had the greatest number of physical conditions with an average of 7.71 per patient, compared to 4.29 in Japan and 4.94 in India.

Table 17
Global Outliers for
Physical Conditions of Patients with Metastatic RCC

| PHYSICAL CONDITION | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | UK | United States |
|---------------------------------------|--------|--------|--------|---------|-------|-------|--------|-------------|-----|---------------|
| NOT AFFECTED | 2% | | 5% | 5% | N/A | 0% | 0% | | | |
| Fatigue | 77% | | | | N/A | | 9% | | | 91% |
| Trouble concentrating | 28% | | | | N/A | 9% | | | | 43% |
| Mucositis/mouth ulcers | 25% | | | | N/A | 12% | | 44% | | |
| Muscle weakness | 39% | | | | N/A | 22% | | | | 47% |
| Pain related to surgery | 24% | | | 12% | N/A | | 42% | 15% | | |
| Bowel changes | 52% | | 60% | | N/A | | 12% | | 60% | 60% |
| Loss of appetite | 39% | | | | N/A | 19% | | 51% | | |
| Changes in taste and smell | 42% | | | | N/A | | 15% | | 52% | 55% |
| Sleeplessness | 36% | | | | N/A | 24% | | 26% | | |
| Itching | 22% | | | | N/A | 10% | | | 30% | |
| Hair loss | 18% | 10% | 10% | | N/A | | 36% | | | |
| Change of hair colour | 33% | | | | N/A | | 15% | | 48% | |
| Memory loss | 17% | | | | N/A | 2% | | 11% | | 24% |
| Changes in sexual function | 20% | | 33% | 33% | N/A | 3% | | | | |
| Aching joints | 28% | | | | N/A | 9% | | | | 43% |
| Sore feet and hands | 36% | | | | N/A | 47% | 30% | 30% | | |
| Weight loss | 30% | | | 43% | N/A | 16% | | | 18% | |
| Cramps | 17% | | 29% | | N/A | 2% | | 4% | | |
| Fluid retention | 13% | | | | N/A | | 27% | 3% | | |
| Skin reactions | 26% | | | | N/A | | | 41% | | |
| Nausea and vomiting | 32% | | | | N/A | 16% | 52% | | 43% | |
| Average no. of conditions per patient | | | | | 4.94 | 4.29 | | | | 7.71 |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- Table 18 shows that patients with no evidence of RCC or who were told they were cured in the UK had the greatest number of physical conditions with an average of 3.41 per patient, compared to 2.46 in Japan.

Table 18
Global Outliers for
Physical Conditions of Patients with
No Evidence of RCC/Told they were Cured

| PHYSICAL CONDITON | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|---------------------------------------|--------|--------|--------|---------|-------|-------|--------|-------------|----------------|---------------|
| NOT AFFECTED | 16% | 30% | | 27% | N/A | | N/A | 5% | | |
| Fatigue | 57% | 46% | 66% | | N/A | | N/A | | | |
| Trouble concentrating | 21% | | | 29% | N/A | | N/A | | | 11% |
| Mucositis/mouth ulcers | 4% | | 2% | 0% | N/A | | N/A | | | |
| Muscle weakness | 19% | | | 12% | N/A | | N/A | 26% | | 20% |
| Pain related to surgery | 34% | | | | N/A | | N/A | 56% | | 24% |
| Bowel changes | 19% | | 28% | | N/A | | N/A | 12% | | |
| Loss of appetite | 8% | | | | N/A | 2% | N/A | | | |
| Changes in taste and smell | 8% | | 4% | | N/A | 12% | N/A | | 4% | |
| Sleeplessness | 27% | 21% | | | N/A | | N/A | 21% | 44% | |
| Itching | 11% | | | | N/A | 5% | N/A | | | 15% |
| Hair loss | 7% | | | | N/A | | N/A | 2% | | 11% |
| Change of hair colour | 5% | | | | N/A | 7% | N/A | | 0% | |
| Memory loss | 9% | | | | N/A | 0% | N/A | | 17% | |
| Changes in sexual function | 10% | | | | N/A | | N/A | 2% | | |
| Aching joints | 16% | | | | N/A | 5% | N/A | | | 24% |
| Sore feet and hands | 10% | | | 2% | N/A | 5% | N/A | | | 12% |
| Weight loss | 12% | | | 4% | N/A | 3% | N/A | 35% | | |
| Cramps | 6% | 9% | | | N/A | 2% | N/A | 2% | 9% | 2% |
| Fluid retention | 9% | 11% | | | N/A | | N/A | 0% | | |
| Skin reactions | 6% | | | | N/A | | N/A | 7% | 2% | |
| Nausea and vomiting | 9% | | | 0% | N/A | | N/A | | 11% | 11% |
| Average no. of conditions per patient | | | | | N/A | 2.46 | N/A | | 3.41 | |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

Psychosocial Issues

- 96% of patients globally were impacted by psychosocial issues.
- As shown in Table 19, disease-related anxiety was the number one psychosocial issue affecting patients, followed by the fear of recurrence.
- Patients in the United States had the greatest number of psychosocial issues with an average of 4.93 per patient, compared to 3.31 in India.
- There are extreme variations between Japan and Mexico for the fear of recurrence (67% versus 40%), and the fear of dying (59% versus 32%).

Table 19
Global Outliers for
Psychosocial Issues

| PSYCHOSOCIAL ISSUE | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | UK | United States |
|---|--------|--------|--------|---------|-------|-------|--------|-------------|-----|---------------|
| NOT AFFECTED | 4% | 8% | | 9% | | | | 0% | | |
| General anxiety | 31% | 38% | | 15% | | | 14% | | | |
| Disease-related anxiety | 60% | | | 44% | | 70% | 27% | | | 70% |
| Fear of dying | 44% | | | 38% | | 59% | 32% | | | |
| Fear of recurrence | 50% | | | | 26% | 67% | 40% | 58% | | |
| Depression | 27% | | | | | 10% | | | | 42% |
| Isolation | 16% | | | 8% | | | | | | 25% |
| Changes in relationships | 28% | | | | 13% | 13% | 41% | | | |
| Difficulty on the job or in school | 19% | | 12% | | 10% | | 28% | | | 26% |
| Stress related to financial issues | 28% | | 11% | 11% | | | | 49% | | |
| Loss or reduction in employment | 20% | | | | | | | 9% | 29% | |
| Difficulty navigating the healthcare system | 14% | | | | | 2% | 20% | | | |
| Problems getting life or health insurance | 13% | | 4% | | | | 36% | | 21% | |
| Concerns about body image/physical appearance | 22% | | | | 14% | 12% | 34% | | | |
| Relationships with friends/others | 18% | | | | 10% | | 27% | | | |
| Sexuality | 14% | | 22% | 22% | | 1% | | | | 22% |
| Average no. of issues per patient | | | | | 3.31 | | | | | 4.93 |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- As shown in Table 20, globally there were no notable differences between males and females for psychosocial issues, with the exception of the fear of recurrence, where this impacted 58% of females and 44% of males.

Table 20
Notable Differences for
Psychosocial Issues by Gender

| PSYCHOSOCIAL ISSUE | Males | Females | Notable Difference |
|---|-------|---------|--------------------|
| NOT AFFECTED | 5% | 4% | |
| General anxiety | 32% | 30% | |
| Disease-related anxiety | 59% | 60% | |
| Fear of dying | 46% | 43% | |
| Fear of recurrence | 44% | 58% | 14% |
| Depression | 26% | 27% | |
| Isolation | 14% | 18% | |
| Changes in relationships | 27% | 29% | |
| Difficulty on the job or in school | 20% | 17% | |
| Stress related to financial issues | 30% | 26% | |
| Loss or reduction in employment | 18% | 21% | |
| Difficulty navigating the healthcare system | 13% | 15% | |
| Problems getting life or health insurance | 12% | 13% | |
| Concerns about body image/physical appearance | 20% | 24% | |
| Relationships with friends/others | 18% | 19% | |
| Sexuality | 15% | 12% | |
| LEGEND | | | |
| Most negative | | | |
| Most positive | | | |

- Table 21 shows that male patients in the United States reported the greatest number of psychosocial issues with an average of 5.05 per patient, compared to 3.22 in Germany.
- There is an extreme variation between Japan and Mexico for the fear of recurrence (62% versus 25%).

Table 21
Global Outliers for
Psychosocial Issues Affecting Males

| PSYCHOSOCIAL ISSUE | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | UK | United States |
|---|--------|--------|--------|---------|-------|-------|--------|-------------|-----|---------------|
| NOT AFFECTED | 5% | | | 12% | | 0% | 0% | | | |
| General anxiety | 32% | 48% | | 12% | | | 16% | 40% | | |
| Disease-related anxiety | 59% | | | | | | 29% | | | 71% |
| Fear of dying | 46% | | | 36% | | 69% | | | | |
| Fear of recurrence | 44% | | | | 24% | 62% | 25% | 55% | | |
| Depression | 26% | | | | | 9% | | | | 41% |
| Isolation | 14% | | | 6% | | 6% | | | | 23% |
| Changes in relationships | 27% | | | | 14% | 12% | | 33% | 33% | |
| Difficulty on the job or in school | 20% | | | 12% | | | | | | 29% |
| Stress related to financial issues | 30% | | | 7% | | | | 51% | | |
| Loss or reduction in employment | 18% | | | | | | | 8% | 30% | |
| Difficulty navigating the healthcare system | 13% | | 6% | | | 1% | 19% | | | |
| Problems getting life or health insurance | 12% | | 3% | | | | 35% | | 20% | |
| Concerns about body image/physical appearance | 20% | | | | 13% | 8% | 27% | | | 27% |
| Relationships with friends/others | 18% | | | | 10% | | 30% | | | 26% |
| Sexuality | 15% | | | | | 1% | | | | 30% |
| Average no. of issues per patient | | | | 3.22 | | | | | | 5.05 |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- Table 22 shows that female patients in the United States reported the greatest number of psychosocial issues with an average of 4.83 per patient, compared to 3.29 in India.
- There is an extreme variation between Japan and other countries for the fear of recurrence (72%).

Table 22
Global Outliers for
Psychosocial Issues Affecting Female Patients

| PSYCHOSOCIAL ISSUE | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | UK | United States |
|---|--------|--------|--------|---------|-------|-------|--------|-------------|-----|---------------|
| NOT AFFECTED | 4% | 8% | 0% | | | | | 0% | | |
| General anxiety | 30% | | | 17% | | | 8% | | | 40% |
| Disease-related anxiety | 60% | | | 35% | | | 25% | 78% | | |
| Fear of dying | 43% | | | | | | 23% | 54% | | |
| Fear of recurrence | 58% | | | | 27% | 72% | | | | |
| Depression | 27% | | | | | 12% | | | | 43% |
| Isolation | 18% | | | 10% | | | | | | 27% |
| Changes in relationships | 29% | | | | 12% | 14% | 53% | | | |
| Difficulty on the job or in school | 17% | | | | 4% | | 30% | | | |
| Stress related to financial issues | 26% | | 12% | | | | | 44% | | |
| Loss or reduction in employment | 21% | | | | 8% | | 28% | | 28% | |
| Difficulty navigating the healthcare system | 15% | | | | | 2% | 22% | | | |
| Problems getting life or health insurance | 13% | | 4% | | | | 40% | | 23% | |
| Concerns about body image/physical appearance | 24% | | | | 16% | | 43% | | | |
| Relationships with friends/others | 19% | | | | 12% | | 27% | 25% | | |
| Sexuality | 12% | | 21% | 19% | | 1% | | | | |
| Average no. of issues per patient | | | | | 3.29 | | | | | 4.83 |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- As shown in Table 23, certain psychosocial issues were more prevalent on a global basis for patients diagnosed 2014 and later.

Table 23
Notable Differences for
Psychosocial Issues by Year of Diagnosis

| PSYCHOSOCIAL ISSUE | Prior to 2014 | 2014 and later | Notable differences |
|---|---------------|----------------|---------------------|
| NOT AFFECTED | 6% | 3% | |
| General anxiety | 27% | 34% | 7% |
| Disease-related anxiety | 56% | 62% | 6% |
| Fear of dying | 38% | 48% | 10% |
| Fear of recurrence | 50% | 51% | |
| Depression | 21% | 30% | 9% |
| Isolation | 16% | 16% | |
| Changes in relationships | 27% | 28% | |
| Difficulty on the job or in school | 19% | 18% | |
| Stress related to financial issues | 21% | 33% | 12% |
| Loss or reduction in employment | 20% | 19% | |
| Difficulty navigating the healthcare system | 11% | 16% | 5% |
| Problems getting life or health insurance | 14% | 12% | |
| Concerns about body image/physical appearance | 22% | 22% | |
| Relationships with friends/others | 18% | 18% | |
| Sexuality | 18% | 12% | 6% |
| LEGEND | | | |
| Most negative | | | |
| Most positive | | | |

- Table 24 shows that patients diagnosed prior to 2014 in the United States reported the greatest number of psychosocial issues with an average of 4.78 per patient, compared to 3.12 in Germany.
- The extreme variation between Japan and Mexico for disease-related anxiety (74% versus 31%) is notable.

Table 24
Global Outliers for
Psychosocial Issues for Patients Diagnosed Prior to 2104

| PSYCHOSOCIAL ISSUE | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|---|--------|--------|--------|---------|-------|-------|--------|-------------|----------------|---------------|
| NOT AFFECTED | 6% | 10% | | 11% | N/A | | 0% | | | |
| General anxiety | 27% | 36% | | 14% | N/A | | | | | |
| Disease-related anxiety | 56% | | | 36% | N/A | 74% | 31% | | | |
| Fear of dying | 38% | | | | N/A | 52% | | 54% | | 32% |
| Fear of recurrence | 50% | | | | N/A | 64% | 43% | | | |
| Depression | 21% | | | | N/A | 10% | | 29% | | 31% |
| Isolation | 16% | | | | N/A | 7% | | 29% | | |
| Changes in relationships | 27% | | | | N/A | 7% | 49% | | | |
| Difficulty on the job or in school | 19% | | 13% | | N/A | | | | | 26% |
| Stress related to financial issues | 21% | | 5% | | N/A | | | 43% | | |
| Loss or reduction in employment | 20% | | 10% | | N/A | | | | 31% | |
| Difficulty navigating the healthcare system | 11% | | 5% | | N/A | 2% | 16% | | | 18% |
| Problems getting life or health insurance | 14% | | 2% | | N/A | | 45% | | | |
| Concerns about body image/physical appearance | 22% | | | 16% | N/A | 5% | 47% | | 27% | |
| Relationships with friends/others | 18% | | | | N/A | 12% | | | 25% | |
| Sexuality | 18% | | | | N/A | 0% | | | | 26% |
| Average no. of issues per patient | | | | 3.12 | N/A | | | | | 4.78 |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- Table 25 shows that patients diagnosed in 2014 and later in the United States reported the largest number of psychosocial issues with an average of 5.01 per patient, compared to 3.30 in India.

- Compared to patients diagnosed prior to 2014 in Japan, disease-related anxiety notably dropped, whereas the fear of dying notably rose.

Table 25
Global Outliers for
Psychosocial Issues for Patients Diagnosed 2014 and Later

| PSYCHOSOCIAL ISSUE | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|---|--------|--------|--------|---------|-------|-------|--------|-------------|----------------|---------------|
| NOT AFFECTED | 3% | 6% | | N/A | | | | 0% | | |
| General anxiety | 34% | | | N/A | | | 12% | | | 40% |
| Disease-related anxiety | 62% | | | N/A | | | 24% | | 71% | 71% |
| Fear of dying | 48% | | | N/A | | 61% | 29% | | 53% | |
| Fear of recurrence | 51% | | | N/A | 25% | 68% | 37% | | | |
| Depression | 30% | | 15% | N/A | | 10% | | | | 48% |
| Isolation | 16% | | | N/A | | 10% | | | 22% | 25% |
| Changes in relationships | 28% | | | N/A | 10% | 15% | 37% | | | |
| Difficulty on the job or in school | 18% | | 9% | N/A | | | 32% | | | |
| Stress related to financial issues | 33% | 21% | 19% | N/A | | | | 51% | | |
| Loss or reduction in employment | 19% | | | N/A | | | 28% | 7% | 28% | |
| Difficulty navigating the healthcare system | 16% | 24% | | N/A | | 1% | | | | |
| Problems getting life or health insurance | 12% | | | N/A | | 5% | 30% | | 18% | |
| Concerns about body image/physical appearance | 22% | | | N/A | 11% | | | | | 29% |
| Relationships with friends/others | 18% | | | N/A | 11% | | 34% | | | |
| Sexuality | 12% | | 21% | N/A | | 1% | | | | |
| Average no. of issues per patient | | | | | 3.30 | | | | | 5.01 |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- Table 26 shows that patients with localised RCC in the United States had the largest number of psychosocial issues with an average of 4.57 per patient, compared to 3.49 in India.
- There are extreme outliers for the fear of recurrence for Japan (84%), and South Korea (80%).

Table 26
Global Outliers for
Psychosocial Issues for Patients with Localised RCC

| PSYCHOSOCIAL ISSUE | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|---|--------|--------|--------|---------|-------|-------|--------|-------------|----------------|---------------|
| NOT AFFECTED | 4% | 24% | 0% | N/A | | 0% | | 0% | N/A | 0% |
| General anxiety | 32% | | 41% | N/A | | | 12% | | N/A | |
| Disease-related anxiety | 53% | 44% | | N/A | | | 29% | 70% | N/A | |
| Fear of dying | 43% | | | N/A | 51% | | 34% | | N/A | |
| Fear of recurrence | 50% | | | N/A | 26% | 84% | | 80% | N/A | |
| Depression | 28% | | 13% | N/A | | 11% | | | N/A | 43% |
| Isolation | 14% | 24% | | N/A | | 5% | | | N/A | |
| Changes in relationships | 26% | | | N/A | 8% | | 42% | | N/A | |
| Difficulty on the job or in school | 17% | | | N/A | | | 29% | 25% | N/A | 7% |
| Stress related to financial issues | 33% | 20% | 9% | N/A | | | | 50% | N/A | |
| Loss or reduction in employment | 16% | | 6% | N/A | | 32% | | | N/A | |
| Difficulty navigating the healthcare system | 17% | | 3% | N/A | | | | | N/A | 29% |
| Problems getting life or health insurance | 17% | | | N/A | | 5% | 34% | | N/A | |
| Concerns about body image/physical appearance | 21% | | | N/A | 15% | | 40% | 7% | N/A | |
| Relationships with friends/others | 17% | | | N/A | 10% | | 29% | | N/A | 29% |
| Sexuality | 8% | | | N/A | | | | 2% | N/A | 21% |
| Average no. of issues per patient | | | | | 3.49 | | | | | 4.57 |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- Table 27 shows that patients with metastatic RCC in the United States had the largest number of psychosocial issues with an average of 5.12 per patient, compared to 3.48 in Japan.

Table 27
Global Outliers for
Psychosocial Issues for Patients with Metastatic RCC

| PSYCHOSOCIAL ISSUE | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|---|--------|--------|--------|---------|-------|-------|--------|-------------|----------------|---------------|
| NOT AFFECTED | 4% | | | 7% | N/A | | 0% | | | |
| General anxiety | 31% | 41% | | 9% | N/A | | 9% | | | |
| Disease-related anxiety | 67% | | | 43% | N/A | | 33% | | 72% | 72% |
| Fear of dying | 51% | | | | N/A | | 30% | 62% | | |
| Fear of recurrence | 33% | | 41% | | N/A | 48% | | | 24% | |
| Depression | 29% | | | | N/A | 7% | | | | 43% |
| Isolation | 19% | | | | N/A | 7% | | | | 31% |
| Changes in relationships | 35% | | | | N/A | 11% | | 42% | | |
| Difficulty on the job or in school | 23% | | 16% | 18% | N/A | | 30% | | | 32% |
| Stress related to financial issues | 33% | | 10% | | N/A | 46% | | 59% | | |
| Loss or reduction in employment | 25% | | | | N/A | | | 7% | 39% | |
| Difficulty navigating the healthcare system | 15% | | 4% | | N/A | 0% | 24% | | | |
| Problems getting life or health insurance | 12% | | 1% | | N/A | | 42% | | 23% | |
| Concerns about body image/physical appearance | 28% | | | 18% | N/A | 13% | | 40% | | |
| Relationships with friends/others | 23% | | | 30% | N/A | 7% | | | | |
| Sexuality | 20% | | | 39% | N/A | 2% | | 5% | | |
| Average no. of issues per patient | | | | | N/A | 3.48 | | | | 5.12 |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- Table 28 shows that patients with no evidence of RCC or who were told they were cured in the United States had the greatest number of psychosocial issues with an average of 4.61 per patient, compared to 3.31 in Germany.
- There is an extreme result for patients in the UK without any evidence of the disease, or who had been told they were cured, for the fear of recurrence (91%).

Table 28
Global Outliers for
Psychosocial Issues for Patients with No Evidence of RCC/ told they were Cured

| PSYCHOSOCIAL ISSUE | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|---|--------|--------|--------|---------|-------|-------|--------|-------------|----------------|---------------|
| NOT AFFECTED | 6% | | | 10% | N/A | | N/A | 0% | 0% | |
| General anxiety | 32% | | | 20% | N/A | | N/A | 42% | | 45% |
| Disease-related anxiety | 54% | | | 43% | N/A | | N/A | 74% | | |
| Fear of dying | 37% | | | | N/A | 62% | N/A | 28% | | |
| Fear of recurrence | 73% | | 65% | | N/A | | N/A | | 91% | |
| Depression | 23% | | | | N/A | 15% | N/A | 23% | | 41% |
| Isolation | 13% | | | 0% | N/A | | N/A | 23% | | 20% |
| Changes in relationships | 22% | | 29% | | N/A | 13% | N/A | | | |
| Difficulty on the job or in school | 16% | | 8% | | N/A | | N/A | 21% | | |
| Stress related to financial issues | 21% | | | 10% | N/A | | N/A | 33% | | |
| Loss or reduction in employment | 16% | 12% | 12% | | N/A | 22% | N/A | | 22% | |
| Difficulty navigating the healthcare system | 10% | | | 2% | N/A | 2% | N/A | | 17% | |
| Problems getting life or health insurance | 13% | | | | N/A | 5% | N/A | 23% | | |
| Concerns about body image/physical appearance | 14% | | | 18% | N/A | 7% | N/A | | | 18% |
| Relationships with friends/others | 14% | 10% | | | N/A | 20% | N/A | | | |
| Sexuality | 11% | | 17% | | N/A | 0% | N/A | 0% | | |
| Average no. of issues per patient | | | | 3.31 | N/A | | | | | 4.61 |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

Patient Timeline- Most Difficult Times

- As shown in Table 29, the process of diagnosis, surgery and recovery and waiting for surgery/scan results were the most difficult times for patients.
- Table 29 shows that patients in Mexico and the United States had the greatest number of difficult times with an average of 2.81 per patient, compared to 2.26 in India.

Table 29
Global Outliers for
Most Difficult Times

| MOST DIFFICULT TIME | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|---|--------|--------|--------|---------|-------|-------|--------|-------------|----------------|---------------|
| NOT AFFECTED | 2% | | 0% | | 7% | | | 0% | | 0% |
| During the process of diagnosis | 51% | | | | 63% | | 24% | 65% | | |
| Surveillance period | 19% | | | 9% | | 31% | | | | |
| Surgery & recovery afterwards | 38% | | | | 27% | 46% | 24% | | | |
| Follow up scans | 17% | | | 30% | | 6% | 31% | 6% | | |
| Waiting for surgery or scan results | 37% | 51% | | | 11% | | | | 56% | |
| Diagnosis of recurrence | 21% | | | | 14% | 29% | | | | |
| Treatment for recurrence | 10% | | | | | | 24% | | 3% | |
| Diagnosis of further disease progression | 23% | | | 28% | | 16% | 35% | | | |
| Dealing with side effects of treatment | 29% | | | | | 21% | 37% | | | |
| Transition to palliative care | 4% | | | | | | 15% | 1% | | |
| Long term adjustment, survivorship | 12% | | | | | 3% | 20% | | | |
| Average no. of most difficult times per patient | | | | | 2.26 | | 2.81 | | | 2.81 |
| LEGEND | | | | | | | | | | |
| Most positive | | | | | | | | | | |
| Most negative | | | | | | | | | | |

- As shown in Table 30, females were affected more notably than males by:
 - Surgery and recovery afterwards,
 - Follow up scans, and by
 - Waiting for surgery or scan results.

- Males were more notably impacted than females by:
 - Diagnosis of further disease progression, and for
 - Dealing with side effects of treatment.

Table 30
Notable Differences for
Most Difficult Times by Gender

| MOST DIFFICULT TIME | Males | Females | Notable Difference |
|--|-------|---------|--------------------|
| NOT AFFECTED | 3% | 1% | |
| During the process of diagnosis | 50% | 51% | |
| Surveillance period | 17% | 20% | |
| Surgery & recovery afterwards | 34% | 42% | 8% |
| Follow up scans | 15% | 20% | 5% |
| Waiting for surgery or scan results | 33% | 42% | 9% |
| Diagnosis of recurrence | 22% | 20% | |
| Treatment for recurrence | 11% | 9% | |
| Diagnosis of further disease progression | 25% | 20% | 5% |
| Dealing with side effects of treatment | 33% | 24% | 9% |
| Transition to palliative care | 4% | 4% | |
| Long term adjustment, survivorship | 12% | 13% | |
| LEGEND | | | |
| Most negative | | | |
| Most positive | | | |

- Table 31 shows that male patients in Mexico had the greatest number of difficult times with an average of 2.78 per patient, compared to 2.23 in India.

Table 31
Global Outliers for
Most Difficult Times for Males

| MOST DIFFICULT TIME | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|---|---------------|---------------|---------------|----------------|--------------|--------------|---------------|--------------------|-----------------------|----------------------|
| NOT AFFECTED | 3% | | | | 11% | | | | | 0% |
| During the process of diagnosis | 50% | | | | | | 27% | 64% | | |
| Surveillance period | 17% | | | 5% | 10% | 31% | | 29% | | |
| Surgery & recovery afterwards | 34% | | | | | 48% | 22% | | 22% | |
| Follow up scans | 15% | | | | | 7% | 30% | 7% | | |
| Waiting for surgery or scan results | 33% | 42% | | | 13% | | | | 54% | |
| Diagnosis of recurrence | 22% | 17% | | | 17% | 32% | | | | |
| Treatment for recurrence | 11% | 5% | | | | | 21% | | 5% | |
| Diagnosis of further disease progression | 25% | | | | | 21% | 37% | 21% | 21% | |
| Dealing with side effects of treatment | 33% | | | | | 24% | | | | 45% |
| Transition to palliative care | 4% | | | | 7% | | 16% | 1% | | |
| Long term adjustment, survivorship | 12% | | | | | 2% | | | 20% | |
| Average no. of most difficult times per patient | | | | | 2.23 | | 2.78 | | | |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- Table 32 shows that female patients in the United States had the greatest number of difficult times with an average of 2.87 per patient, compared to 2.41 in Japan and 2.31 in India.

Table 32
Global Outliers for
Most Difficult Times for Females

| MOST DIFFICULT TIME | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|---|---------------|---------------|---------------|----------------|--------------|--------------|---------------|--------------------|-----------------------|----------------------|
| NOT AFFECTED | 1% | | 0% | 0% | | | 0% | 0% | 3% | |
| During the process of diagnosis | 51% | | | | 69% | | 15% | 66% | | |
| Surveillance period | 20% | | | 15% | | | | | 15% | 35% |
| Surgery & recovery afterwards | 42% | 48% | | | 29% | | 27% | | | |
| Follow up scans | 20% | | | 40% | | 5% | 34% | 3% | | |
| Waiting for surgery or scan results | 42% | 61% | | | 8% | | 31% | | 57% | |
| Diagnosis of recurrence | 20% | | 28% | | 10% | 26% | | | | |
| Treatment for recurrence | 9% | | | | | | 31% | | 1% | |
| Diagnosis of further disease progression | 20% | | | | | 10% | 36% | | | |
| Dealing with side effects of treatment | 24% | 13% | | | | 18% | 37% | | | |
| Transition to palliative care | 4% | | | | | | 15% | 0% | | 0% |
| Long term adjustment, survivorship | 13% | | | | 23% | 4% | | | | |
| Average no. of most difficult times per patient | | | | | 2.31 | 2.41 | | | | 2.87 |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

Communication and Support from Healthcare Professionals

- Of those patients globally who experienced psychosocial issues that had affected their emotional well-being, 50% had not communicated them to a healthcare professional (compared to 72% in South Korea, 66% in Japan, both Global Outliers, and 35% in France).
- Globally,
 - 47% revealed their issues in great detail (compared to 58% in Canada, 26% in Mexico and 25% in India, all Global Outliers),
 - 31% told the doctor about some of their issues, but not to the full extent (compared to 42% in India, a Global Outlier, and 24% in France), and
 - 15% held back some details and minimized their symptoms and side effects, or chose not to communicate their issues at all (compared to 31% in Mexico, 20% in India, and 10% in South Korea, all Global Outliers), and
 - 6% had not had the opportunity to communicate their issues at all (compared to 13% in India, a Global Outlier, and 1% in the United States).
- Globally, of patients who chose to tell the doctor or healthcare professional everything in great detail about their psychosocial issues this was the case for:
 - 27% of those under 30 yrs.,
 - 39% of those 30-45 yrs.²⁹ (compared to 50% in Canada and 29% in India),
 - 49% of those 46-65 yrs.³⁰ (compared to 25% in Mexico and 20% in India, both Global Outliers, and 59% in Canada),
 - 54% of those 66+ yrs. (compared to 67% in France and 36% in India, both Global Outliers),
 - 52% of male patients (compared to 65% in Canada, 59% in France, and 25% in India and Mexico, all Global Outliers), and
 - 42% of female patients (compared to 55% in France and 24% in Mexico).

²⁹ Due to insufficient data, results are not reported for Germany

³⁰ Due to insufficient data, results are not reported for Mexico

- For those who communicated their issues 92% of patients globally found their doctors to be helpful, while this had not been the case for the remaining 8%.
- Of those, 50% found their doctors to be 'very helpful' (compared to 58% in Canada and the United States, both Global Outliers, and 39% in Japan), while 42% found them to be 'somewhat helpful' (compared to 53% in India and 35% in Canada).
- Globally 8% had not found their doctors to be helpful at all (compared to 12% in France and the UK, and 5% in India and Mexico).

Barriers to Receiving Quality Care

- Globally, patients had the following types of healthcare coverage:
 - Government healthcare (73% compared to 31% in the United States and 13% in India, both Global Outliers, and 97% in France),
 - Private insurance (39%, compared to 81% in the United States, a Global Outlier, and 7% in the UK),
 - Self-coverage (14%, compared to 63% in India, a Global Outlier and 0% in Germany), and
 - Family coverage (6%, compared to 47% in India and 10% in South Korea, both Global Outliers and 0% in France).
- As Table 33 shows, 64% of patients in France were not affected by any barriers to receiving quality care compared to 4% in Mexico.
- In fact, patients in Mexico had the greatest number of barriers to receiving quality care with an average of 2.86 per patient, compared to 1.16 in France.
- Globally, lack of affordability and wait time for treatment were the most notable barriers to receiving quality care.

Table 33
Global Outliers for
Barriers to Receiving Quality Care

| BARRIERS TO RECEIVING QUALITY CARE | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|---|---------------|---------------|---------------|----------------|--------------|--------------|---------------|--------------------|-----------------------|----------------------|
| NOT AFFECTED | 39% | | 64% | | | | 4% | | | |
| Lack of affordability, cost of treatment | 21% | | | 1% | 72% | | | 54% | | |
| Lack of access to treatment centre (travel) | 13% | | 5% | | 26% | | 35% | | 5% | |
| Inability to understand the treatment | 6% | | 0% | 0% | 28% | | 33% | | | 0% |
| Lack of access to up-to-date treatment/equipment | 14% | | 4% | 4% | | | 34% | 23% | | |
| Wait time to treatment was longer than necessary | 18% | | | 6% | | | 35% | 30% | | |
| Lack of personal support | 14% | | | | | 7% | 24% | | | |
| No specialty doctor available locally | 13% | | | | | | | 5% | | 22% |
| Difficulty managing career/caregiver role while in treatment | 9% | | 1% | | | | 33% | | | |
| Fear of discrimination by my employer/ friends/ family | 9% | | | | | | 31% | 14% | 5% | |
| No available treatments | 5% | | | | | | 13% | | 1% | |
| Average no. of barriers per patient | | | 1.16 | | | | 2.86 | | | |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- As shown in Table 34, female patients were most affected by wait time to treatment whereas males were most affected by lack of affordability/cost of treatment.
- Females were affected more notably than male patients by the lack of availability of a specialty doctor and difficulty managing their career/caregiver role whereas males were more notably affected by lack of affordability than females.

Table 34
Notable Differences for
Barriers to Receiving Quality Care by Gender

| BARRIER TO RECEIVING QUALITY CARE | Males | Females | Notable Difference |
|--|--------------|----------------|---------------------------|
| NOT AFFECTED | 41% | 38% | |
| Lack of affordability, cost of treatment | 23% | 17% | 6% |
| Lack of access to treatment centre (travel) | 13% | 12% | |
| Inability to understand the treatment | 6% | 7% | |
| Lack of access to the most up to date treatment/equipment | 15% | 13% | |
| Wait time to treatment was longer than necessary | 18% | 19% | |
| Lack of personal support | 13% | 15% | |
| No specialty doctor available locally | 11% | 16% | 5% |
| Difficulty managing career/caregiver role while in treatment | 5% | 13% | 8% |
| Fear of discrimination by my employer/friends/family | 9% | 10% | |
| No available treatments | 6% | 5% | |
| LEGEND | | | |
| Most negative | | | |
| Most positive | | | |

- As shown in Table 35, male patients in Mexico had the greatest number of barriers to receiving quality care with an average of 2.78 per patient, compared to 1.14 in France.
- Patients in India and South Korea were most considerably affected by the lack of affordability and the cost of treatment.

Table 35
Global Outliers for
Barriers to Receiving Quality Care for Males

| BARRIER TO RECEIVING QUALITY CARE | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|--|--------|--------|--------|---------|-------|-------|--------|-------------|----------------|---------------|
| NOT AFFECTED | 41% | | 65% | | 4% | | | | | |
| Lack of affordability, cost of treatment | 23% | | | 0% | 71% | | | 56% | | |
| Lack of access to treatment centre (travel) | 13% | | 5% | | | | 37% | | | |
| Inability to understand the treatment | 6% | | 0% | 0% | 30% | | 27% | | | 0% |
| Lack of access to up-to-date treatment/equipment | 15% | | | 5% | | | 35% | | | |
| Wait time to treatment was longer than necessary | 18% | | | 5% | | | 33% | 31% | | |
| Lack of personal support | 13% | | 5% | 5% | | | 30% | | | |
| No specialty doctor available locally | 11% | | | | 21% | | | 4% | | |
| Difficulty managing career/caregiver role while in treatment | 5% | | 0% | | 1% | | 27% | | | |
| Fear of discrimination by my employer/ friends/ family | 9% | | | | | | 33% | 14% | | 3% |
| No available treatments | 6% | | | | | 10% | 10% | | 1% | |
| Average no. of barriers per patient | | | 1.14 | | | | 2.78 | | | |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- As shown in Table 36, female patients in Mexico had the greatest number of barriers to receiving quality care with an average of 2.95 per patient, compared to 1.15 in France.
- Females in both Mexico and India were most considerably affected by the inability to understand the treatment.

Table 36
Global Outliers for
Barriers to Receiving Quality Care for Females

| BARRIER TO RECEIVING QUALITY CARE | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|--|--------|--------|--------|---------|-------|-------|--------|-------------|----------------|---------------|
| NOT AFFECTED | 38% | | 63% | | | | 2% | | | |
| Lack of affordability, cost of treatment | 17% | | 0% | | 70% | | | | | |
| Lack of access to treatment centre (travel) | 12% | | | 2% | 32% | | 36% | | | |
| Inability to understand the treatment | 7% | | 0% | 0% | 28% | | 42% | | 0% | 0% |
| Lack of access to up-to-date treatment/ equipment | 13% | | 1% | | | | 34% | 29% | | |
| Wait time to treatment was longer than necessary | 19% | | | 8% | | | 36% | 29% | | |
| Lack of personal support | 15% | | | | | 8% | 20% | | 21% | |
| No specialty doctor available locally | 16% | | 6% | | | 6% | 27% | | | 32% |
| Difficulty managing career/caregiver role while in treatment | 13% | | 4% | | | | 39% | | | |
| Fear of discrimination by my employer/ friends/ family | 10% | | | | 0% | | 29% | | | |
| No available treatments | 5% | 1% | | | | 1% | 15% | 10% | 1% | |
| Average no. of barriers per patient | | | 1.15 | | | | 2.95 | | | |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- As shown in Table 37, there were more barriers to receiving quality care for younger patients (under 30 yrs.) and patients aged 30-45 yrs. compared to older age groups of 46+ yrs.

Table 37
Most Negative and Positive Outcomes for
Barriers to Receiving Quality Care by Age

| BARRIER TO RECEIVING QUALITY CARE | Under 30 yrs. | 30-45 yrs. | 46-65 yrs. | 66+ yrs. |
|--|----------------------|-------------------|-------------------|-----------------|
| NOT AFFECTED | 16% | 23% | 41% | 53% |
| Lack of affordability, cost of treatment | 43% | 29% | 19% | 14% |
| Lack of access to treatment centre (travel) | 14% | 18% | 11% | 12% |
| Inability to understand the treatment | 18% | 12% | 5% | 4% |
| Lack of access to the most up to date treatment/equipment | 24% | 15% | 14% | 10% |
| Wait time to treatment was longer than necessary | 27% | 22% | 18% | 15% |
| Lack of personal support | 14% | 20% | 14% | 9% |
| No specialty doctor available locally | 16% | 12% | 14% | 11% |
| Difficulty managing career/caregiver role while in treatment | 12% | 17% | 7% | 5% |
| Fear of discrimination by my employer/friends/family | 14% | 17% | 9% | 4% |
| No available treatments | 8% | 8% | 4% | 4% |
| LEGEND | | | | |
| Most negative | | | | |
| Most positive | | | | |

- As shown in Table 38, patients 30-45 yrs. in Mexico had the greatest number of barriers to receiving quality care with an average of 3.09 per patient, compared to 1.28 in France.

Table 38
Global Outliers for
Barriers to Receiving Quality Care for Patients 30-45 yrs.

| BARRIER TO RECEIVING QUALITY CARE | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|--|--------|--------|--------|---------|-------|-------|--------|-------------|----------------|---------------|
| NOT AFFECTED | 23% | | 59% | N/A | | | 2% | | | |
| Lack of affordability, cost of treatment | 29% | | 0% | N/A | 67% | | | | 0% | |
| Lack of access to treatment centre (travel) | 18% | | | N/A | | | 43% | | 0% | |
| Inability to understand the treatment | 12% | | 0% | N/A | 19% | 0% | 43% | | 0% | 0% |
| Lack of access to up-to-date treatment/equipment | 15% | | 7% | N/A | | | 37% | | | 0% |
| Wait time to treatment was longer than necessary | 22% | | 10% | N/A | | | | 38% | | 10% |
| Lack of personal support | 20% | | | N/A | 31% | 7% | 35% | | | |
| No specialty doctor available locally | 12% | | 3% | N/A | | | 24% | | | |
| Difficulty managing career/caregiver role while in treatment | 17% | | 0% | N/A | | | 37% | | | |
| Fear of discrimination by my employer/ friends/ family | 17% | | | N/A | | | 33% | | | 7% |
| No available treatments | 8% | | | N/A | 14% | | | | 0% | 0% |
| Average no. of barriers per patient | | | 1.28 | N/A | | | 3.09 | | | |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- As shown in Table 39, patients 46-65 yrs. in Mexico and India had the greatest number of barriers to receiving quality care with an average of 2.75 and 2.21 per patient respectively, compared to 1.18 in Germany.

Table 39
Global Outliers for
Barriers to Receiving Quality Care for Patients 46-65 yrs.

| BARRIER TO RECEIVING QUALITY CARE | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|--|--------|--------|--------|---------|-------|-------|--------|-------------|----------------|---------------|
| NOT AFFECTED | 41% | | | 60% | 3% | | | | | |
| Lack of affordability, cost of treatment | 19% | | 1% | 1% | 71% | | | 54% | | |
| Lack of access to treatment centre (travel) | 11% | | | | 27% | | 31% | | 4% | |
| Inability to understand the treatment | 5% | 0% | 0% | 0% | 35% | | 25% | | 0% | 0% |
| Lack of access to up-to-date treatment/equipment | 14% | | 4% | 5% | | | 33% | 24% | | |
| Wait time to treatment was longer than necessary | 18% | | | 5% | | | 38% | | | |
| Lack of personal support | 14% | | | | | 7% | | 21% | 21% | |
| No specialty doctor available locally | 14% | | | | 24% | | | 5% | | 23% |
| Difficulty managing career/caregiver role while in treatment | 7% | | 1% | | | | 35% | | | |
| Fear of discrimination by my employer/ friends/ family | 9% | | | | 3% | | 37% | | 4% | |
| No available treatments | 4% | 2% | | | | | 8% | | 2% | |
| Average no. of barriers per patient | | | | 1.18 | 2.21 | | 2.75 | | | |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- As shown in Table 40, patients 66+ yrs. in South Korea and India had the greatest number of barriers to receiving quality care with an average of 2.64 and 2.42 respectively per patient, compared to 1.05 in France.

Table 40
Global Outliers for
Barriers to Receiving Quality Care for Patients 66+ yrs.

| BARRIER TO RECEIVING QUALITY CARE | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|--|--------|--------|--------|---------|-------|-------|--------|-------------|----------------|---------------|
| NOT AFFECTED | 53% | | 75% | | 8% | | N/A | 8% | | |
| Lack of affordability, cost of treatment | 14% | | | 0% | 75% | | N/A | 64% | | |
| Lack of access to treatment centre (travel) | 12% | | | | | | N/A | 40% | | 2% |
| Inability to understand the treatment | 4% | | 0% | 0% | 33% | | N/A | 24% | | 0% |
| Lack of access to up-to-date treatment/ equipment | 10% | | | 0% | | | N/A | 36% | | |
| Wait time to treatment was longer than necessary | 15% | | | 3% | | 32% | N/A | 36% | | |
| Lack of personal support | 9% | | 3% | | | | N/A | 16% | | |
| No specialty doctor available locally | 11% | | 2% | | 25% | | N/A | | | |
| Difficulty managing career/caregiver role while in treatment | 5% | | | 0% | 8% | 0% | N/A | 24% | 0% | 0% |
| Fear of discrimination by my employer/ friends/ family | 4% | | | | 17% | | N/A | | 0% | 0% |
| No available treatments | 4% | | 0% | 0% | | 11% | N/A | | 0% | |
| Average no. of barriers per patient | | | 1.05 | | 2.42 | | N/A | 2.64 | | |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- As shown in Table 41, overall, patients with other sub-types experienced more barriers to receiving quality care than clear cell RCC patients.

Table 41
Notable Differences for
Barriers to Receiving Quality Care by Sub-Type

| BARRIER TO RECEIVING QUALITY CARE | Clear Cell | Other Sub-Types | Notable Difference |
|--|------------|-----------------|--------------------|
| NOT AFFECTED | 43% | 31% | 12% |
| Lack of affordability, cost of treatment | 21% | 18% | |
| Lack of access to treatment centre (travel) | 11% | 16% | 5% |
| Inability to understand the treatment | 5% | 11% | 6% |
| Lack of access to the most up to date treatment/equipment | 12% | 21% | 9% |
| Wait time to treatment was longer than necessary | 17% | 23% | 6% |
| Lack of personal support | 13% | 16% | |
| No specialty doctor available locally | 13% | 15% | |
| Difficulty managing career/caregiver role while in treatment | 7% | 13% | 6% |
| Fear of discrimination by my employer/friends/family | 7% | 14% | 7% |
| No available treatments | 4% | 9% | 5% |
| LEGEND | | | |
| Most negative | | | |
| Most positive | | | |

- As shown in Table 42, patients with clear cell RCC in India and South Korea had the greatest number of barriers to receiving quality care with an average of 2.25 and 2.02 respectively per patient, compared to 1.15 in France and Germany.

Table 42
Global Outliers for
Barriers to Receiving Quality Care for Clear Cell RCC Patients

| BARRIER TO RECEIVING QUALITY CARE | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|--|--------|--------|--------|---------|-------|-------|--------|-------------|----------------|---------------|
| NOT AFFECTED | 43% | | 65% | | 0% | | N/A | | | |
| Lack of affordability, cost of treatment | 21% | | | 0% | 73% | | N/A | | | |
| Lack of access to treatment centre (travel) | 11% | | | 5% | 18% | | N/A | | 5% | |
| Inability to understand the treatment | 5% | | 0% | 0% | 36% | | N/A | 11% | 0% | 0% |
| Lack of access to up-to-date treatment/equipment | 12% | | | 3% | | | N/A | 18% | | |
| Wait time to treatment was longer than necessary | 17% | | | 5% | 30% | | N/A | | | |
| Lack of personal support | 13% | | | | | 6% | N/A | 20% | 19% | |
| No specialty doctor available locally | 13% | | | | 30% | | N/A | 3% | | |
| Difficulty managing career/caregiver role while in treatment | 7% | | 1% | | | 13% | N/A | 13% | | |
| Fear of discrimination by my employer/ friends/ family | 7% | | | | | | N/A | 14% | 3% | |
| No available treatments | 4% | 0% | | | | 6% | N/A | 6% | | |
| Average no. of barriers per patient | | | 1.15 | 1.15 | 2.25 | | N/A | 2.02 | | |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

- As shown in Table 43, patients with other sub-types of RCC in Mexico had the greatest number of barriers to receiving quality care with an average of 2.91 per patient, compared to 1.23 in Germany.

Table 43
Global Outliers for
Barriers to Receiving Quality Care for RCC Patients with Other Sub-Types

| BARRIER TO RECEIVING QUALITY CARE | Global | Canada | France | Germany | India | Japan | Mexico | South Korea | United Kingdom | United States |
|--|--------|--------|--------|---------|-------|-------|--------|-------------|----------------|---------------|
| NOT AFFECTED | 31% | | 62% | | | | 3% | | | |
| Lack of affordability, cost of treatment | 18% | | 0% | | 66% | | | 54% | 0% | |
| Lack of access to treatment centre (travel) | 16% | | 3% | | 34% | | 38% | | 3% | |
| Inability to understand the treatment | 11% | | 0% | 0% | 28% | 0% | 35% | | 0% | 0% |
| Lack of access to up-to-date treatment/equipment | 21% | | | 7% | | | 36% | 35% | | 7% |
| Wait time to treatment was longer than necessary | 23% | | 10% | 10% | | 39% | | | | |
| Lack of personal support | 16% | | | | 24% | 7% | | | | |
| No specialty doctor available locally | 15% | | | | | 4% | 22% | | | 22% |
| Difficulty managing career/caregiver role while in treatment | 13% | | 0% | | | 18% | 37% | | | |
| Fear of discrimination by my employer/ friends/ family | 14% | | | 3% | | 4% | 34% | | | 13% |
| No available treatments | 9% | | | 3% | 21% | | | | 3% | |
| Average no. of barriers per patient | | | | 1.23 | | | 2.91 | | | |
| LEGEND | | | | | | | | | | |
| Most negative | | | | | | | | | | |
| Most positive | | | | | | | | | | |

V. Opportunities to Improve Care

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

Surveillance

- At the time of the survey, globally, patients were in the following stages of their RCC:
 - 13% were in Stage 1 or 2 (compared to 36% in India, 25% in Mexico, both Global Outliers, and 3% in Germany),
 - 8% were in Stage 3 (compared to 36% in India and 33% in Mexico, both Global Outliers, and 1% in the United States),
 - 40% were in Stage 4 (compared to 25% in Mexico, 17% in India, both Global Outliers, and 53% in the United States),
 - 19% had no evidence of the disease (compared to 32% in Japan and 1% in India),
 - 10% had been told they were cured (compared to 20% in Germany and 18% in France, both Global Outliers, and 3% in Japan, the UK and the United States), and
 - 4% had died (compared to 10% in France and Germany and 1% in the United States, all Global Outliers).

- Globally, their last follow-up scan had occurred:
 - Less than one year ago (85% compared to 41% in Mexico, a Global Outlier, and 95% in Japan),
 - 1-3 years ago (9% compared to 38% in Mexico and 3% in Japan, both Global Outliers), and
 - More than 3 years ago (4% compared to 16% in Mexico, a Global Outlier, and 1% in India, South Korea and the United States).

- Most recent follow up scans had occurred more than three years ago for:
 - 3% of those in Stage 1 or 2 (compared to 17% in Mexico a Global Outlier),
 - 6% of those in Stage 3,

- 2% of those in Stage 4 (compared to 24% in Mexico a Global Outlier, and 2% in Japan),
- 5% of those who had no evidence of the disease or who had been told they were cured (compared to 11% in the UK and 0% in South Korea, both Global Outliers),
- 27% of those who had died,

- 6% of those under 30 yrs.,
- 3% of those aged 30-45 yrs. (compared to 17% in Mexico, a Global Outlier and 0% in Canada, South Korea, the UK and the United States),
- 4% of those aged 46-65 (compared to 7% in France and 0% in India, both Global Outliers),
- 6% of those aged 66+ yrs. (compared to 14% in the UK a Global Outlier and 0% in India and South Korea),

- 4% of males (compared to 13% in Mexico, a Global Outlier and 1% in Canada, India and the United States),
- 5% of females (compared to 17% in Mexico, a Global Outlier and 0% in India and South Korea),

- 5% of those with no understanding of kidney cancer guidelines (compared to 14% in Mexico, a Global Outlier and 0% in Germany and the United States), and
- 5% of those with no understanding of the guidelines for kidney cancer follow up (compared to 13% in France, a Global Outlier and 0% in Germany and the United States).

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 globally 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.

29% of patients globally had their treatment plans decided for them solely by their doctors. Shared decision making was least evident in India and the UK, and considerably more prevalent in Mexico and the United States. Patients who had their treatment decisions decided for them solely by their doctors were being treated both at major cancer centres and in community/local general hospitals (45% and 34% respectively).

Lack of shared decision making affected higher proportions of younger patients, and those in later stages of their disease. There is evidence to suggest that shared decision making may actually have deteriorated in Japan, the UK and the United States for patients diagnosed since 2016.

- Globally, 29% of patients had not been engaged at all in their treatment plans, in that their doctor had decided their treatment plan for them (compared to 42% in India, 38% in the UK, 22% in the United States and 14% in Mexico, all Global Outliers),
- Globally, of those patients who were involved in their treatment decision:
 - 6% made the decision by themselves (compared to 9% in France, a Global Outlier, and 3% in Japan),
 - 51% made a joint decision with their doctors (compared to 63% in the United States, and 38% in India), and
 - 12% were asked for input from their doctors (compared to 39% in Mexico, 20% in South Korea and 4% in Germany, all Global Outliers).

- Globally, the following helped patients with their treatment plans³¹:
 - Partner/spouse (56%, compared to 9% in Mexico and 42% in Germany, both Global Outliers, and 70% in France),
 - Parents (13%, compared to 27% in Mexico, and 3% in Germany, both Global Outliers),
 - Children (21%, compared to 29% in France and 10% in Germany, both Global Outliers),
 - Friends/other family members (20%, compared to 30% in South Korea and 6% in Germany, both Global Outliers),
 - Local family doctor (22% compared to 38% in France, a Global Outlier, and 8% in the UK), and
 - A patient organisation (12% compared to 34% in South Korea, 4% in France and 3% in Mexico, all Global Outliers).

- 18% of patients made the decision by themselves (compared to 29% in Japan and Germany, and 10% in Mexico, all Global Outliers), and for 4%, the decision had rested on their personal financial situation (compared to 8% in South Korea, a Global Outlier, 0% in Germany and 1% in the UK).

- Globally, of those patients who reported “My doctor decided for me”:³²
 - 34% were being treated in community/local or general hospitals (compared to 65% in Japan and 10% in India, both Global Outliers),
 - 45% at major cancer centres³³ (compared to 74% in South Korea and 31% in Japan, and
 - 9% at private clinics (compared to 24% in India, a Global Outlier, and 0% in South Korea).

- In the case where treatment plans were decided solely by the doctor without any input from the patient this affected:
 - 35% of those under 30 yrs.,
 - 28% of those 30-45 yrs. (compared to 41% in the UK, 36% in India, and 11% in Mexico, all Global Outliers),
 - 30% of those 46-65 yrs. (compared to 46% in India, 38% in the UK, and 19% in Canada, all Global Outliers), and

³¹ Due to insufficient sample sizes, data is not reported for India.

³² Due to insufficient sample sizes, data is not reported for Germany or Mexico

³³ Includes 30% of major cancer centres with kidney cancer specialists, (compared to 66% in South Korea, 18% in Japan and 23% in the UK, all Global Outliers),

- 27% of those 66+ yrs. (compared to 38% in India and 15% in Germany).
- 28% of male patients³⁴ (compared to 43% in India, 42% in the UK, and 15% in Mexico, all Global Outliers), had their treatment decisions made for them by their doctors, as had
- 30% of females (compared to 42% in India, 34% in the UK, 22% in the United States, and 15% in Mexico, all Global Outliers).

- 25% of patients in Stage 1 or 2 (compared to 39% in India, a Global Outlier and 11% in France),
- 20% of those in Stage 3,
- 30% of those in Stage 4 (compared to 39% in the UK, 20% in the United States, and 16% in Mexico, all Global Outliers),
- 31% of those with no evidence of the disease or who were told they were cured (compared to 39% in the UK, 36% in South Korea, and 22% in the United States, all Global Outliers), and
- 29% of those who had died.

- Table 44 shows shared decision making by year of diagnosis.

- For example, shared decision making was notably better in Canada for patients diagnosed in 2016 and after (with 7% fewer patients reporting 'My Doctor Decided for Me').

³⁴ Due to insufficient sample sizes, data is not reported for Germany or Mexico

Table 44
Notable Differences for
Shared decision making by Year of Diagnosis

| DOCTOR DECIDED FOR THE PATIENT | Prior to 2016 | 2016 and After | Notable differences |
|---------------------------------------|----------------------|-----------------------|----------------------------|
| GLOBAL | 28% | 30% | |
| Canada | 28% | 21% | 7% |
| France | 27% | 25% | |
| Japan | 25% | 33% | 8% |
| UK | 35% | 43% | 8% |
| United States | 18% | 27% | 9% |
| LEGEND | | | |
| Most negative | | | |
| Most positive | | | |

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APPENDIX

Methodology

Data Collection

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

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

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

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

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

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

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

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

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

Derived Questions

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

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

Outliers

Outliers were used in two ways in the analysis:

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

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

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

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