2018 IKCC PATIENT SURVEY
-Mexico-

Prepared for:
International Kidney Cancer Coalition
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TABLE OF CONTENTS

Preface

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

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

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

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

[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.

2. Tables of Notable Difference

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

'Most negative' (red) and 'most positive' (green) results are indicated in the chart legends and refer to what could be construed as most positive and most negative outcomes for RCC patients. Where there is no implied positive or negative implication for patients, the colours are as in the chart legend.

3. Order of Magnitude

These tables contain similar information, however there is no implied 'most negative' or 'most positive' result; they simply bring attention to absolute differences between categories.

Country vs. Global Results

All results in this report are for India, unless otherwise specified as either 'Global Outliers' or 'notable differences' to global results.

INTRODUCTION

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

Kidney cancer (renal cell carcinoma or RCC) is the seventh most common histological type of cancer in the Western world[3] and has shown a sustained increase in its global prevalence thereby presenting an increasing burden to health systems, governments, and most of all to individual patients and their families. Although therapies have improved for both early-stage and late-stage RCC patients, little is known about the variations in the patient experience and best practices among countries.

The 2018 survey has been specifically designed to identify geographic variations in patient education, experience and awareness, access to care, quality of life and involvement in clinical trials so that opportunities for improvement can be identified, and programs developed to better meet the needs of patients. This is achieved through examination of each of the following issues:

Knowledge and Understanding

- To what degree were patients aware of and did they have an understanding of their diagnosis, including stage, sub-type, treatment options, and expected side effects?
- Were patients made aware of advancements in the treatment of RCC?
- How successful was the healthcare profession in diagnosing RCC in a timely manner?

Clinical Trials

- To what extent were healthcare professionals proactive in discussing clinical trials with their patients?
- Of those patients who were not approached, what was the missed opportunity and how could these patients potentially be reached?
- When was the option of a clinical trial first discussed with patients?

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

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

Quality of Care

- To what extent were patients treated for their RCC, and where had they been receiving treatment?
- What specific physical and psychosocial issues were patients living with? Did these issues differ depending upon the patient's gender or the year they were diagnosed?
- To what extent were patients communicating and reaching out for help for their issues?
- How helpful was the healthcare profession in providing support to patients who were impacted by the side effects of treatment?
- How and to what degree were patients affected during their patient timeline? Who was more notably affected?
- Which barriers stood in their way to receiving treatment? Who were more affected by these barriers?

Opportunities to Improve Care

- Are there any opportunities to improve the care, survivorship and surveillance of RCC patients?
- Are there opportunities to improve patients' awareness of guidelines for quality kidney cancer care and follow-up?
- Who were the patients who reported that their last follow up scan was more than 3 years ago?

Shared decision making

- How engaged were patients in deciding their treatment plans?
- Did this engagement vary by factors such as place of treatment, age or gender?

KEY FINDINGS- Mexico

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

- With best practices in mind, explore communication practices of the healthcare community in Mexico which, relative to global results, appear to be more successful in providing newly diagnosed patients with not only an understanding of various aspects of RCC, but also information about the possibility of patient participation in clinical trials;

- Contribute to the advancement of kidney cancer research and potentially enhance the survivorship of patients:
    - By encouraging the healthcare community to take advantage of a virtually untapped resource of a potential pool of individuals who would be willing to participate in clinical trials, should they be asked, and by
    - Enhancing the awareness and understanding of patients about clinical trials to ensure they are equipped and comfortable in making a decision about participating.

- Contribute to improving the quality of life of RCC patients by encouraging them to share with their doctors their experiences about how kidney cancer has impacted their lives, and provide patients with the resources and tools for the psychological support they need;

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

- Bring specific attention and focus to the particular struggles of patient sub groups that may for whatever reason go unnoticed by the healthcare community, such as females, patients with rarer sub-types, older patients and localised RCC patients, so that they too might benefit from a better patient experience and overall quality of life;

- Improve survivorship by empowering patients through education to advocate for regular surveillance despite gender, age or stage; and

- Advocate for shared decision making for patient treatment plans through further development of decision aid tools where there is evidence of physician directed care.

SURVEY RESULTS- Mexico

I. Respondent Profile

Total response rate:

- A total of 1983 individuals responded to the IKCC 2018 Global Patient Survey, including patients and caregivers from 43 countries around the world.

Respondent Demographic Profile:

- Mexico had 144 respondents, or 7% of the global total.

- 58% of those responding to the survey were kidney cancer patients (71% globally), while the remaining 42% defined themselves as a caregiver, family member or friend of the patient (29% globally).

- 49% of respondents were males, 48% were females and 3% did not self-identify.

- Survey respondents had the following age profile:
  - Under 18 (8% a Global Outlier, compared to 1% globally),
  - 18-29 (10% a Global Outlier, compared to 2% globally),
  - 30-45 (35% compared to 20% globally),
  - 46-65 (41% a Global Outlier, compared to 57% globally), and
  - 66+ (7% compared to 20% globally).

- Survey respondents were in the following stages of kidney cancer:
  - Localised kidney cancer (60% a Global Outlier, compared to 23% globally),
  - Metastatic (26% a Global Outlier, compared to 44% globally), and
  - No evidence/told they were cured (14% a Global Outlier, compared to 33% globally).

II. Knowledge and Understanding

IKCC and its Affiliate Organisations can play an instrumental role in advocating for the early and universal diagnosis of all RCC patients, and in enhancing the knowledge and understanding of all patient subgroups, including those who fall outside the more commonly accepted definition of a typical RCC patient.

It is imperative that patients in Mexico 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.

Mexico appears unique in that its patients, upon diagnosis, had among the best understanding of certain aspects of their disease. This suggests an opportunity for the IKCC to explore best practices.

54% of patients in Mexico were not told their sub-type upon initial diagnosis, among one of the poorest results globally for this foundational piece of information of which all RCC patients should be aware. However, compared to patients globally, patients in Mexico had considerably more of an understanding of their sub-type and their likelihood of survival upon initial diagnosis, and patients with other sub-types had the best understanding of various aspects of their disease per patient.

Compared to global results, considerably fewer patients in Mexico were diagnosed in 3 months or less, with older patients (66+ yrs.) taking notably the longest to be correctly diagnosed.

Year of Diagnosis

- Mexican patients who responded to this survey had been diagnosed in the following years:
  - 1% prior to 2005 (7% globally),
  - 1% in 2005,
  - 1% in 2006,
  - 1% in 2007,
  - 3% in 2008,
  - 2% in 2009,
  - 4% in 2010,
  - 9% in 2011,
  - 8% in 2012,
  - 12% in 2013 (a Global Outlier, compared to 7% globally),
  - 15% in 2014 (a Global Outlier, compared to 8% globally),
  - 15% in 2015 (10% globally),
  - 15% in 2016, and,
  - 12% in 2017 (a Global Outlier, compared to 20% globally), and
  - 2% in 2018.

Success of Timely Diagnosis

- Patients in Mexico were in the following stages of their kidney cancer when they were first diagnosed:
  - 28% in Stages 1 or 2 , still only within the kidney (a Global Outlier, compared 53% globally),
  - 39% in Stage 3, cancer was still locally advanced (a Global Outlier, compared to 20% globally), and
  - 33% in Stage 4, cancer had spread (26% globally).

- Following their first visit to the doctor, 10% of Mexican patients were correctly diagnosed in less than a month (a Global Outlier, compared to 52% globally), while
  - 16% were diagnosed in 1-3 months (a Global Outlier, compared to 26% globally),
  - 23% in 3-6 months (a Global Outlier, compared to10% globally),
  - 26% in 6 months to a year (a Global Outlier, compared to 6% globally), and
  - 26% in more than one year (a Global Outlier, compared to 6%. globally).

- 12% of patients in Mexico were diagnosed at a family doctor or GP's office (20% globally),
  - 8% at an emergency department,
  - 35% at a community, local or general hospital,
  - 32% at a major cancer centre[4] (13% globally),
  - 12% at a private clinic, and
  - 0% at some other facility.

- According to Table 1, there was no notable difference between males and females for a diagnosis of less than three months.

Table 1
Notable Differences for
Time of Diagnosis by Gender

TIME OF DIAGNOSIS	Male	Female	Notable Differences
Less than month	6%	14%	8%
1-3 months	18%	13%	5%
3-6 months	26%	20%	6%
6 months-1 year	26%	25%	
More than 1 year	23%	28%	5%
LEGEND			
Most negative			
Most positive			

- As shown in Table 2, patients 66+ yrs. took the longest to be diagnosed in less than three months (20% a Global Outlier, compared to 83% globally) followed by:
  - 23% of those under 30 yrs. (a Global Outlier, compared to 52% globally),
  - 26% of those 30-45 yrs. (a Global Outlier, compared to 73% globally), and
  - 28% of those 46-65 yrs. (a Global Outlier compared to 79% globally).

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

Table 2
Notable Differences for
Time of Diagnosis by Age

TIME OF DIAGNOSIS	Under 30 yrs.	30-45 yrs.	46-65 yrs.	66+ yrs.
Less than month	5%	11%	11%	10%
1-3 months	18%	15%	17%	10%
3-6 months	27%	28%	20%	10%
6 months-1 year	23%	26%	24%	40%
More than 1 year	27%	21%	28%	30%
LEGEND				
Most negative				
Most positive				

Patient Knowledge and Understanding

- After their initial diagnosis 54% of Mexican patients were not told their sub-type (a Global Outlier, compared to 38% globally), and they had no understanding of their:
  - Stage (12% compared to 20% globally),
  - Sub-type[5] (23% a Global Outlier, compared to 43% globally),
  - Treatment options (17%),
  - Treatment recommendations (14% compared to 19% globally), or of
  - The risk of recurrence (22% compared to 28% globally), or of their
  - The likelihood of survival (14% a Global Outlier, compared to 25% globally).

- As shown in Table 3, at the time of diagnosis, patients in Mexico with other sub-types had the least understanding about their sub-type and the risk of recurrence.

- However, compared to patients in other countries, patients in Mexico with other sub-types had among the best understanding of various aspects of their disease per patient.[6]

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

Table 3
Lack of Patient Understanding at Time of Diagnosis for Other Sub-types

NO UNDERSTANDING	Other Sub-types
Stage	11%
Sub-type	20%
Treatment options	16%
Treatment recommendations	13%
Risk of recurrence	18%
Likelihood of survival	14%
LEGEND	
Most negative	
Most positive	

- At the time of the survey, 8% of patients in Mexico were still not aware of their sub-type.

- The 82% who were aware reported the following RCC sub-types[7]:
  - Clear cell (14% compared to 62% globally),
  - Papillary (10%),
  - Chromophobe (9%),
  - Unclassified (15%),
  - XP11 Translocation Type (5%),
  - VHL (8%),
  - Renal Medullary (6%),
  - Collecting Duct (9%),
  - Transitional Cell Carcinoma (5%),
  - Renal Sarcoma (3%),
  - Wilms Tumour (5%),
  - Benign Tumour (3%),
  - Other (0%).

[7] Mexican patients had a disproportionate number of patients compared to other countries surveyed.

- At the time of the survey, patients in Mexico also had no understanding of the following:
  - Biopsies for kidney cancer (15% compared to 20% globally),
  - Surgical options (24% compared to 8% globally),
  - Immunotherapy (23%),
  - Targeted therapies (17% compared to 23% globally),
  - Radiation therapies (19% a Global Outlier compared to 29% globally),
  - Ablative therapies (16% compared to 41% globally),
  - Palliative care (15% a Global Outlier compared to 33% globally),
  - Active surveillance (25%),
  - Nutrition/lifestyle (23% a Global Outlier, compared to 14% globally),
  - Complementary therapies (21% a Global Outlier, compared to 39% globally),
  - Guidelines for kidney cancer care (20%), or for
  - Guidelines for kidney cancer follow up (16%).

III. Clinical Trials

Every kidney cancer patient in Mexico deserves access to the highest quality care AND the opportunity to participate in research thereby advancing the quality of care of patients, increasing and advancing kidney cancer research. There was a high degree of willingness amongst patients in Mexico to participate should they be asked, and interest in moving this research forward through clinical trials.

There is a clear opportunity to tap more heavily into this pool of individuals who may consider participating in a trial by providing them with the necessary information at crucial stages of their treatment pathway that would both motivate them and make them feel comfortable in advocating for their own treatment decisions.

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

Clinical trials in Mexico are discussed with patients earlier in the patient timeline, i.e. upon diagnosis, suggesting the opportunity to explore best practices.

Although clinical trials were discussed with notably more patients in Mexico compared to patients globally, 88% had never been asked to participate in a clinical trial, this suggesting that the healthcare community in Mexico has not been proactive in approaching RCC patients about their participation in cancer research.

The fact that 79% 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 a decision, indicates an obvious lost opportunity to improve the quality of care and survivorship of RCC patients.

Although the majority of patients in Mexico had the option of a clinical trial discussed with them after surgery or other treatments rather than upon initial diagnosis, compared to global results considerably more patients

had clinical trials discussed with them upon initial diagnosis. This opens up the possibility of exploring best practices with the healthcare community in Mexico. There is an opportunity however to make patients more aware of the risks and benefits of participating, to ensure greater likelihood of participation.

Patients who HAD DISCUSSIONS about clinical trials

- According to survey results, clinical trials had not been discussed with 16% of patients in Mexico (33% globally).

- Of those who had discussions about clinical trials, those discussions had occurred with:
  - Another patient (11%),
  - Doctors (43% a Global Outlier, compared to 75% globally),
  - Spouses, friends or family (23% compared to 31% globally),
  - Nurses (14%),
  - Patient organisations (10% a Global Outlier, compared to 19% globally), and
  - Online groups (11%).

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

- 88% of patients in Mexico had never been asked to participate in a clinical trial (70% globally).

- Of Mexican patients who had never been asked to participate in a clinical trial, 79% said it said it 'fairly likely'[8] they would do so if asked (a Global Outlier, compared to 89% globally).

- Of the patients in Mexico who said they would be fairly likely[9] to do so, they were being treated at:
  - Community/ local /general hospitals (29% compared to 37% globally),
  - Major cancer centres[10] (56% compared to 45% globally),
  - 12% at private clinics (6% globally), and
  - 0% at 'other'.

[8] 'Fairly likely is the combined result of 'Likely' and 'Maybe; would need more information'.
[9] 'Fairly likely' is the combined result of 'Likely' and 'Maybe; would need more information'.
[10] Including major cancer centres with kidney cancer specialists (20% compared to 30% globally).

- Of the 79% of Mexican patients who said it would be 'fairly likely' they would participate in a clinical trial:
  - 29% said they would be 'likely' to participate (a Global Outlier compared to 38% globally), while
  - 71% 'would require more information to make a decision of whether or not to do so', (a Global Outlier compared to 62% globally)

- Of patients in Mexico who said they would need more information before they agreed to participate in a clinical trial, those patients were being treated at:
  - Community/ local /general hospitals (32% compared to 38% globally),
  - Major cancer centres[11] (56% compared to 44% globally),
  - Private clinics (10%), and
  - Other (0%).

- Of those patients in Mexico who would be 'fairly likely' to participate in a clinical trial if asked, this would be the case for[12]:
  - 80% of patients with localised RCC (87% globally), and
  - 79% of those with metastatic RCC (a Global Outlier, compared to 92% globally).

- 89% of patients in Mexico with other sub-types (77% globally) had never been asked to participate in a clinical trial.

- Patients being treated for other sub-types who had never been approached to participate in a clinical trial were being treated at:
  - Community/local or general hospitals (12% compared to 28% globally),
  - Major cancer centres[13] (65% compared to 47% globally),
  - Private clinics (21% a Global Outlier, compared to 9% globally), and
  - Other (0% compared to 9% globally).

[11] Including major cancer centres with kidney cancer specialists (23% compared to 30% globally)
[12] Due to insufficient data results are not reported for patients who had no evidence of the disease or who had been told they were cured
[13] Including major cancer centres with kidney cancer specialists (22% compared to 30% globally),

Patients who HAD BEEN ASKED to participate in a clinical trial

- Of the patients in Mexico who had been asked to participate in a clinical trial:
  - 0% of their initial discussions were with another patient (a Global Outlier, compared to 9% globally),
  - 67% with doctors (a Global Outlier, compared to 88% globally),
  - 8% with spouses, family or friends (31% globally),
  - 33% with nurses (a Global Outlier, compared to 15% globally),
  - 8% with patient organisations (18% globally),
  - 0% with online groups (16% globally),
  - 8% had no previous discussion with anyone (a Global Outlier, compared to 2% globally), and
  - 0% with 'other'.

- The option of a clinical trial had first been discussed with:
  - 42% upon diagnosis (24% globally),
  - 25% of patients after surgery (a Global Outlier, compared to 49% globally),
  - 25% after other treatments, and
  - 8% who were left with no other treatment options.

- When the option of a clinical trial was discussed with patients:
  - 17% understood very well the risks and benefits of participating (47% globally),
  - 67% had at least some understanding (41% globally), and
  - 17% had a very limited understanding (12% globally).

- Those patients who had either never been asked to participate in a clinical trial or who had declined their participation provided the following reasons for their unwillingness to participate:
  - Lack of enough information to make a decision (22%),
  - Not eligible for the trial (11% compared to 21% globally),
  - Distrust of clinical trials (26% compared to 21% globally),
  - Fear of placebo (30% compared to 18% globally),
  - Fear of uncertainty (30%),
  - Extra tests or interventions required (26% compared to 18% globally),
  - Geographic distance (22% compared to 16% globally),

- Affordability, financial costs (19% a Global Outlier, compared to 7% globally),
- Not available at my hospital (30% a Global Outlier, compared to14% globally),
- Toxicity of treatment (33% a Global Outlier, compared to 22% globally), and
- Other (4% compared to 16% globally).

IV. Quality of Care

Kidney cancer has a profound effect on the lives of patients in Mexico as demonstrated by the impact of physical conditions, psychosocial issues, difficult times, and the barriers standing in the way of receiving quality care. However, there is evidence to suggest that certain physical conditions and psychosocial issues of patients in Mexico may be improving over time.

There is strong evidence to suggest that RCC patients in Mexico are choosing to 'suffer in silence' from the effects of their disease, not reaching out to their healthcare teams for the support they need to improve the quality of their lives. This constitutes a clear call to both IKCC and the healthcare community to encourage conversations with patients about how kidney cancer has affected their lives. Particular attention must be paid to more heavily impacted patient sub groups such as females, and those in the localised stage of the disease who often go unnoticed by the healthcare community, to ensure universal psychosocial support for all patients.

There is a role for IKCC and its Affiliate Organisations to play in Mexico to advocate for change and to provide support for patients who struggle with barriers to quality care particularly since patients in Mexico are impacted by the highest number of barriers per patient compared to patients in other countries.

98% of patients in Mexico were affected by physical conditions, psychosocial issues and by 'most difficult times' that had affected their well-being since initial diagnosis. In fact, compared to patients globally, considerably more patients in Mexico were impacted by physical conditions and were affected by among the greatest *number of difficult times per patient.*

Although male and female patients have a similar biological experience with RCC, they experienced very different physical conditions, psychosocial issues and difficult times as a result of the disease. Compared to patients globally, female patients in Mexico were impacted

by the greatest number of physical conditions per patient, males by the greatest number of 'difficult times' per patient.

Results suggest that patients diagnosed in 2014 and later in Mexico were less notably affected by specific physical conditions and psychosocial issues than patients diagnosed prior to that time, suggesting that certain impacts could be improving over time.
It is surprising that patients with localised RCC were impacted more notably than metastatic patients for a number of physical conditions. In fact, localised patients in Mexico were impacted by the greatest number of physical conditions per patient compared to global results.

Despite the fact that 98% of patients in Mexico were impacted by psychosocial issues and a very high percentage were finding their doctors to be helpful when they did reach out, compared to global results, notably fewer were communicating their issues to a healthcare professional. Compared to global results, considerably fewer middle aged and male patients communicated the full extent of their emotional issues to their doctors.

Patients in Mexico including those with other sub-types were impacted by the greatest number of barriers to receiving quality care per patient than their counterparts in other countries. Younger patients in Mexico (30-45 yrs.) were affected less notably overall by barriers to receiving quality care than older age groups

Treatment for Kidney Cancer

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

- At the time of the survey, 2% of patients in Mexico had not been receiving any treatments at all (7% globally).

- As shown in Table 4, for their first treatment,
  - 27% received them from community/local or general hospitals (47% globally),
  - 52% at major cancer centres[14] (38% globally),
  - 19% from private clinics (a Global Outlier, compared to 7% globally), and
  - 0% from other treatment centres.

- Of those patients in Mexico who had been receiving treatments since that time:
  - 29% had been receiving them from community/local or general hospitals,
  - 50% from major cancer centres[15],
  - 19% from private clinics (a Global Outlier, compared to 7% globally), and
  - 0% at other treatment centres.

- As shown in the table, there was no notable migration of patients initially treated at community/local or general hospitals to major cancer centres after their initial diagnosis.

[14] Including major cancer centres with kidney cancer specialists (16% a Global Outlier compared to 26% globally),
[15] Including major cancer centres with kidney cancer specialists (17% compared to 36% globally)

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

PLACE OF TREATMENT	First Treatment	Subsequent Treatments	Notable Differences
Community/local/general hospitals	27%	29%	
Major cancer centres	52%	50%	
Private clinics	19%	19%	
Other	0%	0%	

Physical Conditions

- As can be seen in Table 5, compared to global results, notably more Mexican patients had been impacted overall by conditions affecting their physical well-being since their initial diagnosis.

- Of those who were impacted, nausea and vomiting was the condition affecting them the most.

- Patients in Mexico were impacted considerably more than patients globally by a number of physical conditions affecting their well-being including:
  - Itching,
  - Hair loss,
  - Memory loss,
  - Fluid retention,
  - Skin reactions, and
  - Nausea and vomiting.

- They were impacted notably less by trouble concentrating and by bowel changes compared to patients globally, and notably more for a number of other physical conditions listed in the Table 5.

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

PHYSICAL CONDITIONS	Global	Mexico	Notable Differences
NOT AFFECTED	8%	2%	6%
Fatigue	66%	18%	48%
Trouble concentrating	24%	17%	7%
Mucositis/mouth ulcers	17%	22%	5%
Muscle weakness	32%	33%	
Pain related to surgery	29%	34%	5%
Bowel changes	33%	23%	10%
Loss of appetite	25%	34%	9%
Changes in taste and smell	25%	22%	
Sleeplessness	31%	29%	
Itching	17%	25%	8%
Hair loss	13%	26%	13%
Change of hair colour	17%	17%	
Memory loss	13%	24%	11%
Changes in sexual function	15%	25%	10%
Aching joints	22%	29%	7%
Sore feet and hands	23%	29%	6%
Weight loss	24%	28%	
Cramps	11%	16%	5%
Fluid retention	12%	23%	11%
Skin reactions	17%	28%	11%
Nausea and vomiting	22%	48%	26%
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- As can be seen in Table 6, male patients in Mexico were more notably impacted than female patients by fatigue, muscle weakness and by changes in sexual function.

- Female patients were more notably impacted than males by a number of physical conditions affecting their well-being that are detailed in the Table.

Table 6
Notable Differences in Mexico for
Physical Conditions by Gender

PHYSICAL CONDITION	Males	Females	Notable Differences
NOT AFFECTED	2%	0%	
Fatigue	25%	8%	17%
Trouble concentrating	19%	17%	
Mucositis/mouth ulcers	16%	31%	15%
Muscle weakness	40%	25%	15%
Pain related to surgery	22%	47%	25%
Bowel changes	17%	25%	8%
Loss of appetite	33%	37%	
Changes in taste and smell	11%	34%	23%
Sleeplessness	24%	36%	12%
Itching	25%	27%	
Hair loss	25%	27%	
Change of hair colour	14%	20%	6%
Memory loss	24%	24%	
Changes in sexual function	29%	24%	5%
Aching joints	27%	34%	7%
Sore feet and hands	21%	41%	20%
Weight loss	27%	31%	
Cramps	13%	19%	6%
Fluid retention	24%	22%	
Skin reactions	22%	36%	14%
Nausea and vomiting	48%	49%	
LEGEND			
Most negative			
Most positive			

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

- For example, Mexican male patients were considerably better off dealing with changes in taste and smell than female patients in other countries.

- Female patients in Mexico were impacted by among the greatest number of physical conditions per patient compared to female patients in other countries.[16]

[16] For further details see the IKCC Global Report

Table 7
Global Outliers for Mexico
Physical Conditions by Gender

PHYSICAL CONDITION	Males	Females
Fatigue	25%	8%
Mucositis/mouth ulcers		31%
Pain related to surgery		47%
Loss of appetite		37%
Changes in taste and smell	11%	34%
Itching		27%
Hair loss	25%	27%
Memory loss	24%	24%
Changes in sexual function		24%
Sore feet and hands		41%
Weight loss		31%
Cramps		19%
Fluid retention	24%	22%
Skin reactions		36%
Nausea and vomiting	48%	49%
LEGEND		
Negative Global Outlier for Mexico		
Positive Global Outlier for Mexico		

- Table 8 shows notable differences between patients diagnosed prior to 2014 and those diagnosed 2014 and later by physical conditions.

- Compared to those diagnosed prior to 2014, those diagnosed 2014 and later were more impacted by:
  - Trouble concentrating,
  - Muscle weakness,
  - Sleeplessness,
  - Itching,
  - Cramps, and by
  - Nausea and vomiting.

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

PHYSICAL CONDITION	Prior to 2014	2014 and Later	Notable Differences
NOT AFFECTED	0%	3%	
Fatigue	16%	18%	
Trouble concentrating	10%	22%	12%
Mucositis/mouth ulcers	20%	24%	
Muscle weakness	30%	36%	6%
Pain related to surgery	48%	24%	24%
Bowel changes	22%	24%	
Loss of appetite	36%	33%	
Changes in taste and smell	30%	17%	13%
Sleeplessness	24%	32%	8%
Itching	22%	28%	6%
Hair loss	36%	20%	16%
Change of hair colour	26%	11%	15%
Memory loss	22%	24%	
Changes in sexual function	36%	18%	18%
Aching joints	38%	24%	14%
Sore feet and hands	30%	29%	
Weight loss	36%	24%	12%
Cramps	8%	21%	13%
Fluid retention	28%	20%	8%
Skin reactions	36%	22%	14%
Nausea and vomiting	42%	53%	11%
LEGEND			
Most negative			
Most positive			

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

- For example, Mexican patients diagnosed prior to 2014 were considerably worse off in dealing with pain related to surgery than patients diagnosed prior to 2014 in other countries.

Table 9
Global Outliers for Mexico
Physical Conditions by Year of Diagnosis

PHYSICAL CONDITION	Prior to 2014	2014 and Later
NOT AFFECTED	0%	
Fatigue	16%	18%
Trouble concentrating	10%	
Pain related to surgery	48%	
Bowel changes	22%	
Itching		28%
Hair loss	36%	20%
Memory loss		24%
Changes in sexual function	36%	
Sore feet and hands	30%	
Cramps		21%
Fluid retention	28%	20%
Skin reactions	36%	
Nausea and vomiting	42%	53%
LEGEND		
Negative Global Outlier for Mexico		
Positive Global Outlier for Mexico		

- Table 10 shows notable differences between patients in stages of RCC by physical conditions.

- For example, patients with localised RCC were impacted notably more by fatigue compared to those who with metastatic RCC.

Table 10
Notable Differences in Mexico for
Physical Conditions by Stage[17]

PHYSICAL CONDITION	Localised RCC	Metastatic RCC	Notable differences
NOT AFFECTED	1%	0%	
Fatigue	18%	9%	9%
Trouble concentrating	21%	12%	9%
Mucositis/mouth ulcers	19%	27%	8%
Muscle weakness	33%	33%	
Pain related to surgery	31%	42%	11%
Bowel changes	26%	12%	14%
Loss of appetite	33%	36%	
Changes in taste and smell	25%	15%	10%
Sleeplessness	25%	36%	11%
Itching	26%	27%	
Hair loss	22%	36%	14%
Change of hair colour	14%	15%	
Memory loss	25%	21%	
Changes in sexual function	29%	30%	
Aching joints	28%	36%	8%
Sore feet and hands	29%	30%	
Weight loss	26%	30%	
Cramps	19%	15%	
Fluid retention	22%	27%	5%
Skin reactions	29%	24%	5%
Nausea and vomiting	44%	52%	8%
LEGEND			
Most negative			
Most positive			

[17] Due to insufficient data results are not reported for patients with no evidence of the disease or who had been told they were cured.

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

- For example, Mexican patients with localised RCC were considerably worse off for loss of appetite than patients with localised RCC in other countries.

- Patients in Mexico with localised RCC were impacted by the greatest number of physical conditions per patient compared to localised RCC patients in other countries[18].

Table 11
Global Outliers for Mexico
Physical Conditions by Stage[19]

PHYSICAL CONDITION	Localised RCC	Metastatic RCC
NOT AFFECTED		0%
Fatigue	18%	9%
Pain related to surgery		42%
Loss of appetite	33%	
Bowel Changes		12%
Changes in taste and smell		15%
Itching	26%	
Hair loss	22%	36%
Memory loss	25%	
Changes in sexual function	29%	
Aching joints	28%	
Change of hair colour		15%
Sore feet and hands	29%	
Fluid retention	22%	27%
Nausea and vomiting	44%	52%
LEGEND		
Negative Global Outlier for Mexico		
Positive Global Outlier for Mexico		

[18] Further detail is available in the IKCC Global Report
[19] Due to insufficient data, results are not reported for patients who had no evidence of the disease or who had been told they were cured.

Psychosocial Issues

- As can be seen in Table 12, 2% of Mexican patients had not had their sense of emotional well-being impacted by psychosocial issues since their initial diagnosis.

- Of those impacted, changes in relationships and the fear of recurrence were the issues affecting them the most.

- Compared to patients globally, patients in Mexico were more notably affected by:
  - Stress related to financial issues,
  - Loss or reduction in employment, and by
  - Difficulty managing the healthcare system.

- They were impacted considerably more than patients globally by:
  - Changes in relationships,
  - Difficulty on the job or in school,
  - Problems getting life or health insurance,
  - Concerns about body image, and by
  - Relationships with friends/others.

- They were considerably less impacted than patients globally by:
  - General and disease related anxiety,
  - The fear of dying, and by
  - Fear of recurrence.

Table 12
Notable Differences between Mexico and Global Results for Psychosocial Issues

PSYCHOSOCIAL ISSUE	Global	Mexico	Notable Differences
NOT AFFECTED	4%	2%	
General anxiety	31%	14%	17%
Disease-related anxiety	60%	27%	33%
Fear of dying	44%	32%	12%
Fear of recurrence	50%	40%	10%
Depression	27%	28%	
Isolation	16%	20%	
Changes in relationships	28%	41%	13%
Difficulty on the job or in school	19%	28%	9%
Stress related to financial issues	28%	34%	6%
Loss or reduction in employment	20%	25%	5%
Difficulty navigating the healthcare system	14%	20%	6%
Problems getting life or health insurance	13%	36%	23%
Concerns about body image/physical appearance	22%	34%	12%
Relationships with friends/others	18%	27%	9%
Sexuality	14%	13%	
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- According to Table 13, male patients in Mexico were impacted notably more than female patients by:
  - General anxiety,
  - The fear of dying, and by
  - Depression.

- Females were more notably impacted than males by:
  - The fear of recurrence,
  - Changes in relationships,
  - Problems getting life or health insurance, and by
  - Concerns about body image/physical appearance.

Table 13
Notable Differences in Mexico for
Psychosocial Issues by Gender

PSYCHOSOCIAL ISSUE	Males	Females	Notable Differences
NOT AFFECTED	0%	2%	
General anxiety	16%	8%	8%
Disease-related anxiety	29%	25%	
Fear of dying	38%	23%	15%
Fear of recurrence	25%	55%	30%
Depression	37%	22%	15%
Isolation	19%	22%	
Changes in relationships	32%	53%	21%
Difficulty on the job or in school	27%	30%	
Stress related to financial issues	35%	35%	
Loss or reduction in employment	24%	28%	
Difficulty navigating the healthcare system	19%	22%	
Problems getting life or health insurance	35%	40%	5%
Concerns about body image/physical appearance	27%	43%	16%
Relationships with friends/others	30%	27%	
Sexuality	16%	12%	
LEGEND			
Most negative			
Most positive			

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

- For example, overall male patients in Mexico were considerably less impacted by the fear of recurrence than male patients in other countries.

Table 14
Global Outliers for Mexico
Psychosocial Issues by Gender

PSYCHOSOCIAL ISSUE	Males	Females
General anxiety	16%	8%
Disease-related anxiety	29%	25%
Fear of dying		23%
Fear of recurrence	25%	
Changes in relationships		53%
Difficulty on the job or in school		30%
Problems getting life or health insurance	35%	40%
Concerns about body image/physical appearance	27%	43%
Relationships with friends/others	30%	27%
LEGEND		
Negative Global Outlier for Mexico		
Positive Global Outlier for Mexico		

- As shown in Table 15, patients who were diagnosed in 2014 and later were more notably impacted than those diagnosed prior to 2014 by:
  - Depression,
  - Difficulty on the job or in school,
  - Loss/reduction in employment,
  - Difficulty navigating the healthcare system,
  - Relationships with friends/other, and by
  - Sexuality.

- Patients who were diagnosed prior to 2014 were more notably affected by a number of psychosocial issues than patients diagnosed 2014 and later as listed in Table 15.

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

PSYCHOSOCIAL ISSUE	Prior to 2014	2014 and Later	Notable Differences
NOT AFFECTED	0%	3%	
General anxiety	18%	12%	6%
Disease-related anxiety	31%	24%	7%
Fear of dying	35%	29%	6%
Fear of recurrence	43%	37%	6%
Depression	24%	32%	8%
Isolation	27%	16%	11%
Changes in relationships	49%	37%	12%
Difficulty on the job or in school	24%	32%	8%
Stress related to financial issues	39%	30%	9%
Loss/reduction in employment	22%	28%	6%
Difficulty navigating the health care system	16%	22%	6%
Problems getting life or health insurance	45%	30%	15%
Concerns about body image/physical appearance	47%	25%	22%
Relationships with friends/other	18%	34%	16%
Sexuality	10%	16%	6%
LEGEND			
Most negative			
Most positive			

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

- For example, Mexican patients diagnosed before 2014 were considerably worse off in coping with changes in relationships than patients diagnosed 2014 and later in other countries.

Table 16
Global Outliers for Mexico
Psychosocial Issues by Year of Diagnosis

PSYCHOSOCIAL ISSUE	Prior to 2014	2014 and Later
General anxiety		12%
Disease-related anxiety	31%	24%
Fear of dying		29%
Fear of recurrence	43%	37%
Changes in relationships	49%	
Difficulty on the job or in school		32%
Difficulty navigating the health care system	16%	
Problems getting life or health insurance	45%	30%
Concerns about body image/physical appearance	47%	
Relationships with friends/other		34%
LEGEND		
Negative Global Outlier for Mexico		
Positive Global Outlier for Mexico		

- Table 17 details specific psychosocial issues affecting Mexican patients' emotional well-being in various stages of RCC.

- For example, patients with localised RCC were more notably impacted than metastatic RCC patients by:
  - The fear of recurrence,
  - Concerns about body image, and by
  - Relationships with friends/others.

- Patients with metastatic RCC were impacted notably more by:
  - Loss or reduction of employment,
  - Problems getting life/health insurance, and from
  - Sexuality.

Table 17
Notable Differences between Stage of RCC for Psychosocial Issues in Mexico[20]

PSYCHOSOCIAL ISSUE	Localised RCC	Metastatic RCC	Notable Differences
NOT AFFECTED	1%	0%	
General anxiety	12%	9%	
Disease-related anxiety	29%	33%	
Fear of dying	34%	30%	
Fear of recurrence	42%	36%	6%
Depression	32%	30%	
Isolation	18%	21%	
Changes in relationships	42%	39%	
Difficulty on the job or in school	29%	30%	
Stress related to financial issues	34%	33%	
Loss or reduction in employment	25%	30%	5%
Difficulty navigating the healthcare system	22%	24%	
Problems getting life or health insurance	34%	42%	8%
Concerns about body image/physical appearance	40%	27%	13%
Relationships with friends/others	29%	21%	8%
Sexuality	7%	21%	14%
LEGEND			
Most negative			
Most positive			

- Table 18 illustrates Global Outliers for patients' psychosocial issues by stage.

- For example, localised RCC patients were considerably more impacted by concerns about body image and physical appearance than patients with localised RCC in other countries.

[20] Due to insufficient data results are not reported for patients who had no evidence of the disease/were told they had been cured.

Table 18
Global Outliers for Mexico
Psychosocial Issues by Stage

PSYCHOSOCIAL ISSUE	Localised RCC	Metastatic RCC
General anxiety	12%	9%
Disease-related anxiety	29%	33%
Fear of dying	34%	30%
Difficulty on the job or in school	29%	30%
Problems getting life or health insurance	34%	42%
Concerns about body image/physical appearance	40%	
Relationships with friends/other	29%	
LEGEND		
Negative Global Outlier for Mexico		
Positive Global Outlier for Mexico		

Patient Timeline- Most Difficult Times

- According to Table 19, Mexican patients experienced their most difficult time during their experience dealing with the side effects of treatment and with diagnosis of further disease progression.

- They were affected considerably less than patients globally:
  - During the process of diagnosis, and by
  - Surgery and recovery afterwards.

- They were considerably more affected than patients globally by a number of difficult times as indicated by the Global Outliers in the Table.

- They were less notably affected than patients globally waiting for surgery or scan results.

- Compared to patients globally, patients in Mexico were affected by among the greatest number of difficult times per patient.[21]

[21] Further information is detailed in the IKCC Global Report.

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

MOST DIFFICULT TIME	Global	Mexico	Notable Differences
NOT AFFECTED	2%	2%	
During the process of diagnosis	51%	24%	27%
Surveillance period	19%	16%	
Surgery & recovery afterwards	38%	24%	14%
Follow up scans	17%	31%	14%
Waiting for surgery or scan results	37%	29%	-8%
Diagnosis of recurrence	21%	24%	
Treatment for recurrence	10%	24%	14%
Diagnosis of further disease progression	23%	35%	12%
Dealing with side effects of treatment	29%	37%	8%
Transition to palliative care	4%	15%	11%
Long term adjustment, survivorship	12%	20%	8%
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- As shown in Table 20, females in Mexico were more notably affected than male patients during:
  - The surveillance period,
  - Surgery and recovery afterwards, and
  - Treatment for recurrence.

- Male patients were more notably affected than females during the process of diagnosis.

Table 20
Notable Differences in Mexico for
Most Difficult Times by Gender

MOST DIFFICULT TIME	Males	Females	Notable Differences
NOT AFFECTED	3%	0%	
During the process of diagnosis	27%	15%	12%
Surveillance period	13%	19%	6%
Surgery and recovery afterwards	22%	27%	5%
Follow up scans	30%	34%	
Waiting for surgery or scan results	29%	31%	
Diagnosis of recurrence	24%	22%	
Treatment for recurrence	21%	31%	10%
Diagnosis of further disease progression	37%	36%	
Dealing with side effects of treatment	38%	37%	
Transition to palliative care	16%	15%	
Long term adjustment, survivorship	19%	20%	
LEGEND			
Most negative			
Most positive			

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

- For example, both male and female Mexican patients were considerably worse off in dealing with follow up scans than male and female patients in other countries.

- Male patients in Mexico had the greatest number of reported 'most difficult times' per patient than other male patients globally[22].

[22] For further details see the IKCC Global Report

Table 21
Global Outliers for Mexico
Most Difficult Times by Gender

MOST DIFFICULT TIME	Males	Females
During the process of diagnosis	27%	15%
Surgery & recovery afterwards	22%	27%
Follow up scans	30%	34%
Waiting for surgery or scan results		31%
Treatment for recurrence		31%
Diagnosis of further disease progression	37%	36%
Dealing with side effects of treatment		37%
Transition to palliative care	16%	15%
LEGEND		
Negative Global Outlier for Mexico		
Positive Global Outlier for Mexico		

Communication and Support from Healthcare Professionals

- Of those patients in Mexico who experienced psychosocial issues 44% communicated their issues to a healthcare professional (50% globally), while 56% did (50% globally).

- In Mexico:
  - 26% were very open and told the doctor everything in great detail (a Global Outlier, compared to 47% globally),
  - 34% shared some of their issues, but not to the full extent,
  - 31% held back some details and minimized their symptoms and side effects or chose not to communicate their issues at all (a Global Outlier, compared to 15% globally), and
  - 8% had not had the opportunity to communicate their issues at all.

- Of patients in Mexico who chose to tell the doctor or everything in great detail about their psychosocial issues this was the case for:
  - 25% of male patients (a Global Outlier, compared to 52% globally),
  - 24% of female patients (42% globally),
  - 22% of those under 30 yrs. (27% globally),

- 31% of those aged 30-45 yrs. (39% globally), and
- 25% of patients[23] aged 46-65 yrs. (a Global Outlier, compared to 49% globally).

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

- Of those, 50% found them to be very helpful, and 45% somewhat helpful (42% globally).

Barriers to Receiving Quality Care

- Patients in Mexico had the following types of healthcare coverage:
  - Government healthcare (67% compared to 73% globally),
  - Private insurance (19%, compared to 39% globally),
  - Self-coverage (12%), and
  - Family coverage (5%).

- As Table 22 shows, 96% of patients in Mexico faced barriers to receiving quality care (61% globally).

- Lack of access to treatment centres and wait times to treatment were the most formidable barriers to receiving quality care.

- Compared to patients globally, patients in Mexico were impacted notably more overall by the lack of locally available specialty doctors.

- They were impacted considerably more than patients globally by a number of barriers as indicated by the Global Outliers.

- Compared to patients globally, patients in Mexico were affected by the greatest number of barriers to receiving quality care per patient.[24]

[23] Due to insufficient sample sizes, data was not reported for the 66+ yr. age bracket.
[24] Further details are available in the IKCC Global Report.

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

BARRIER TO RECEIVING QUALITY CARE	Global	Mexico	Notable Differences
NOT AFFECTED	39%	4%	35%
Lack of affordability, cost of treatment	21%	24%	
Lack of access to treatment centre (travel)	13%	35%	22%
Inability to understand the treatment	6%	33%	27%
Lack of access to up-to-date treatment/equipment	14%	34%	20%
Wait time to treatment was longer than necessary	18%	35%	17%
Lack of personal support	14%	24%	10%
No specialty doctor available locally	13%	20%	7%
Difficulty managing career/caregiver role while in treatment	9%	33%	24%
Fear of discrimination by my employer/ friends/ family	9%	31%	22%
No available treatments	5%	13%	8%
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- According to Table 23, younger patients (30-45 yrs.) in Mexico were affected, overall, less notably by barriers to receiving quality care than older age groups.

Table 23
Notable Differences in Mexico for
Barriers to Receiving Quality Care by Age[25]

BARRIER TO RECEIVING QUALITY CARE	Under 30 yrs.	30-45 yrs.	46-65 yrs.
NOT AFFECTED	10%	2%	4%
Lack of affordability, cost of treatment	29%	15%	27%
Lack of access to treatment centre (travel)	29%	43%	31%
Inability to understand the treatment	38%	43%	25%
Lack of access to up-to-date treatment/equipment	24%	37%	33%
Wait time to treatment was longer than necessary	43%	26%	38%
Lack of personal support	19%	35%	19%
No specialty doctor available locally	14%	24%	19%
Difficulty managing career/caregiver role while in treatment	19%	37%	35%
Fear of discrimination by my employer/ friends/ family	14%	33%	37%
No available treatments	14%	13%	8%
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

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

- For example, Mexican patients under 30 yrs. were considerably better off overall for barriers to receiving quality care, and by a lack of personal support than patients under 30 yrs. in other countries.

- Mexican patients in all reported age groups experienced the greatest number of barriers to care per patient compared to other countries.[26]

[25] Due to insufficient sample size, data is not reported for the 66+ yrs. age bracket.
[26] For further detail see the IKCC Global Report.

Table 24
Global Outliers Mexico results for
Barriers to Receiving Quality Care by Age

BARRIER TO RECEIVING QUALITY CARE	Under 30 yrs.	30-45 yrs.	46-65 yrs.
NOT AFFECTED	10%		
Lack of access to treatment centre (travel)	29%	43%	31%
Inability to understand the treatment	38%	43%	25%
Lack of access to up-to-date treatment/equipment	24%	37%	33%
Wait time to treatment was longer than necessary	43%		38%
Lack of personal support	19%	35%	
No specialty doctor available locally	14%	24%	
Difficulty managing career/caregiver role while in treatment	19%	37%	35%
Fear of discrimination by my employer/ friends/ family	14%	33%	37%
No available treatments	14%		8%
LEGEND			
Negative Global Outlier for Mexico			
Positive Global Outlier for Mexico			

- Table 25 shows notable differences for barriers to receiving quality care in Mexico by gender.

- For example, in Mexico, male patients were more notably affected by lack of affordability and the cost of treatment, and for a lack of personal support than female patients.

- Female patients were more notably affected by:
  - Inability to understand the treatment,
  - Lack of a locally available specialty doctor,
  - Difficulty managing career/caregiver role during treatment, and by
  - Lack of available treatments.

Table 25
Notable Differences in Mexico for
Barriers to Receiving Quality Care by Gender

BARRIER TO RECEIVING QUALITY CARE	Males	Females	Notable Differences
NOT AFFECTED	5%	2%	
Lack of affordability, cost of treatment	27%	15%	12%
Lack of access to treatment centre (travel)	37%	36%	
Inability to understand the treatment	27%	42%	15%
Lack of access to up-to-date treatment/equipment	35%	34%	
Wait time to treatment was longer than necessary	33%	36%	
Lack of personal support	30%	20%	10%
No specialty doctor available locally	14%	27%	13%
Difficulty managing career/caregiver role while in treatment	27%	39%	12%
Fear of discrimination by my employer/ friends/ family	33%	29%	
No available treatments	10%	15%	5%
LEGEND			
Most negative			
Most positive			

- Table 26 shows Global Outliers for barriers to receiving quality care in Mexico by gender.

- For example, females were considerably worse off for having a locally available specialty doctor than female patients in other countries.

- Both male and female patients in Mexico experienced the greatest number of barriers to receiving quality care per patient than males and females in other countries.[27]

[27] For further details see the IKCC Global Report

Table 26
Global Outliers Mexico results for
Barriers to Receiving Quality Care by Gender

BARRIERS TO RECEIVING QUALITY CARE	Males	Females
Lack of access to treatment centre (travel)	37%	36%
Inability to understand the treatment	27%	42%
Lack of access to up-to-date treatment/equipment	35%	34%
Wait time to treatment was longer than necessary	33%	36%
Lack of personal support	30%	20%
No specialty doctor available locally		27%
Difficulty managing career/caregiver role while in treatment	27%	39%
Fear of discrimination by my employer/ friends/ family	33%	29%
No available treatments		15%
LEGEND		
Negative Global Outlier for Mexico		
Positive Global Outlier for Mexico		

- Patients in Mexico with other sub-types were affected considerably more by a number of barriers than their counterparts in other countries as indicated by the Global Outliers.

- They experienced the greatest number of barriers to receiving quality care per patient than patients their counterparts in other countries.[28]

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

Table 27
Notable Differences between Mexico and Global Results
Barriers to Receiving Quality Care for
Patients with Other Sub-types

BARRIER TO RECEIVING QUALITY CARE	Global	Other sub-types	Notable Differences
NOT AFFECTED	31%	3%	28%
Lack of affordability, cost of treatment	18%	18%	
Lack of access to treatment centre (travel)	16%	38%	22%
Inability to understand the treatment	11%	35%	24%
Lack of access to up-to-date treatment/equipment	21%	36%	15%
Wait time to treatment was longer than necessary	23%	36%	13%
Lack of personal support	16%	22%	6%
No specialty doctor available locally	15%	22%	7%
Difficulty managing career/caregiver role while in treatment	13%	37%	24%
Fear of discrimination by my employer/ friends/ family	14%	34%	20%
No available treatments	9%	13%	
LEGEND			
Negative			
Positive			

V. Opportunities to Improve Care

Surveillance for patients in Mexico is considerably poorer compared to patients in other countries. There is an opportunity for IKCC and its Affiliate Organisations to improve survivorship of patients in Mexico by empowering patients through education to advocate for regular surveillance despite gender, age or stage.

Surveillance

- At the time of the survey, patients in Mexico were in the following stages of their RCC:
  - 25% were in Stage 1 or 2 (a Global Outlier, compared to 13% globally),
  - 33% in Stage 3 (a Global Outlier, compared to 8% globally),
  - 25% in Stage 4 (a Global Outlier, compared to 40% globally),
  - 6% had no evidence of the disease (19% globally), and
  - 8% told they were cured, and
  - 2% had died.

- Their last follow up scan had occurred:
  - Less than one year ago (41% a Global Outlier, compared to 85% globally),
  - 1-3 years ago (38% a Global Outlier, compared to 9% globally), and
  - More than 3 years ago (16% a Global Outlier, compared to 4%).

- Most recent follow up scans had occurred more than three years ago at a:
  - Community, local or general hospital (15% compared to 10% globally),
  - At a cancer centre[29] (60% compared to 28% globally), and
  - At a private clinic (25% compared to 7% globally).

- Most recent follow up scans had occurred more than three years ago for:
  - 17% of those in Stage 1 or 2[30] (a Global Outlier, compared to 3% globally),
  - 12% of those in Stage 3 (6% globally),
  - 24% of those in Stage 4 (a Global Outlier, compared to 2% globally),

[29] Includes 40% at a cancer centre with a kidney cancer specialist

[30] Due to insufficient data, results are not reported for those with no evidence of the disease or who had been told they were cured, or for patients who have died

- 5% of those under 30 yrs.[31]
- 17% of those aged 30-45 yrs. (a Global Outlier, compared to 3% globally),

- 13% of males (a Global Outlier, compared to 4% globally),
- 17% of females, (a Global Outlier, compared to 5% globally),

- 14% of those with no understanding of kidney cancer guidelines (a Global Outlier, compared to 5% globally), and
- 6% of those with no understanding of the guidelines for kidney cancer follow up.

[31] Due to insufficient sample size, data is not reported for the 46+ yr. age brackets.

VI. Shared decision making

Although there is evidence to suggest that there is considerably better shared decision making for patients in Mexico compared to patients globally, as this phenomena becomes increasingly recognized as a pillar of patient-centered healthcare, IKCC and its Affiliate Organisations have the opportunity to play a key role to advocate for and support shared decision making for patient treatment plans through further development of decision aid tools where there is evidence of notable physician directed care.

- 14% of patients in Mexico were not engaged at all in their treatment plans, in that their doctor had decided their treatment plan for them (a Global Outlier, compared to 29% globally).

- Of those patients who were involved in their treatment decision:
  - 5% made the decision by themselves,
  - 40% made a joint decision with their doctors (51% globally), and
  - 39% were asked for input from their doctors (a Global Outlier, compared to 12% globally).

- The following helped Mexican patients with their treatment plans:
  - Partner/spouse (9% a Global Outlier, compared to 56% globally),
  - Parents (27% a Global Outlier, compared to 13% globally),
  - Children (24%),
  - Friends/other family members (21%),
  - Local family doctor (22%), and
  - A patient organisation (3% a Global Outlier, compared to 12% globally).

- 10% of patients made the decision by themselves (a Global Outlier, compared to 18% globally), and for 4%, the decision had rested on their personal financial situation.

- In the case where treatment plans were decided solely by the doctor without any input from the patient this affected:[32]
  - 16% of those under 30 yrs. (35% globally),
  - 11% of those aged 30-45 yrs. (28% globally),

  - 13% of those in Stage 1 or 2[33] (25% globally),
  - 7% of those in Stage 3 (20% globally),
  - 16% of those in Stage 4 (a Global Outlier, compared to 30% globally),

  - 15% of males (a Global Outlier, compared to 28% globally),
  - 15% of females (a Global Outlier, compared to 30% globally), and for

  - 15% of those diagnosed prior to 2016 (a Global Outlier, compared to 28% globally)[34].

[32] Due to insufficient sample size, data is not reported for the 46+ age brackets
[33] Due to insufficient sample sizes, data is not available for patients with no evidence of the disease or who had been told they were cured, or who had died.
[34] Due to insufficient sample size results are not reported for patients diagnosed 2016 and after

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

APPENDIX

Methodology

Data Collection

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

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

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

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

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

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

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

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

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

Derived Questions

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

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

Outliers

Outliers were used in two ways in the analysis:

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

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

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

List of Tables