2018 IKCC PATIENT SURVEY
-France -

Prepared for:

International Kidney Cancer Coalition

January 2019

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Preface

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

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

Perception Insight (PI)[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

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[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?

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[2] www.ikcc.org

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

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

Quality of Care

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

Opportunities to Improve Care

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

Shared decision making

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

KEY FINDINGS- France

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;

- Explore best practices in France related to healthcare communication with patients upon their diagnosis to enhance patient knowledge and understanding about their disease, particularly for sub-type;

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

- Contribute to improving the quality of life of RCC patients by encouraging them to share with their doctors their experiences about how kidney cancer has impacted their lives, and provide patients with the resources and tools for the psychological support they need particularly in light of the fact that psychosocial issues may be worsening over time;

- Advocate for change, and support patients who struggle with barriers standing in the way of receiving quality care, potentially using France as an example of best practices;

- Bring specific attention and focus to patient sub groups who may for whatever reason go unnoticed by the healthcare community, and to their particular struggles so that they too might benefit from a better patient experience and overall quality of life;

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

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

SURVEY RESULTS- France

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:

- France had 238 respondents, or 12% of the global total.

- 78% of those responding to the survey were kidney cancer patients (71% globally) while the remaining 22% defined themselves as a caregiver, family member or friend of the patient.

- 59% of respondents were males (54% globally), 40% were females (45% globally), and 1% did not self-identify.

- Survey respondents had the following age profile:
  - Under 18 (0%),
  - 18-29 (1%),
  - 30-45 (15% compared to 20% globally),
  - 46-65 (53%), and
  - 66+ (31% compared to 20% globally).

- Survey respondents were in the following stages of kidney cancer:
  - Localised kidney cancer (18% compared to 23% globally),
  - Metastatic (51% compared to 44% globally), and
  - No evidence/told they were cured (30%).

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 France 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.

Given the very notable positive results of France for patients' general understanding of their disease upon initial diagnosis compared to other countries surveyed, there is a possibility to explore best practices related to healthcare communication with patients during this crucial period of the patient timeline.

Compared to global results, upon diagnosis, RCC patients in France had the greatest understanding per patient about their disease as well as their treatment and guidelines. Patient knowledge and understanding about their sub-type was also notably greater in comparison to global averages.

Despite these positive results, compared to other areas of disease-related understanding, patients in France possessed the least understanding for their sub-type, a foundational piece of information of which all RCC patients should be aware upon diagnosis.

Younger patients (30-45 yrs.) as well as female patients in France took the longest to be correctly diagnosed with RCC. Since these patients fall outside the expected demographic of an RCC patient (typically older and male), they may therefore go unnoticed by the healthcare community.

Year of Diagnosis

- French patients who responded to this survey had been diagnosed in the following years:
  - 12% prior to 2005 (a Global Outlier, compared to 7% globally),
  - 4% in 2005,
  - 2% in 2006,
  - 2% in 2007,
  - 4% in 2008,
  - 7% in 2009,
  - 7% in 2010,
  - 5% in 2011,
  - 7% in 2012,
  - 10% in 2013,
  - 4% in 2014,
  - 7% in 2015,
  - 8% in 2016 (13% globally),
  - 14% in 2017 (20% globally), and
  - 6% in 2018 (12% globally).

Success of Timely Diagnosis

- Patients in France were in the following stages of their kidney cancer when first diagnosed:
  - 60% were in Stages 1 or 2, still only within the kidney (53% globally)
  - 19% in Stage 3, cancer was still locally advanced, and
  - 21% in Stage 4, the cancer had spread (26% globally).

- Following their first visit to the doctor, 57% of French patients were correctly diagnosed in less than a month (52% globally), while
  - 23% were diagnosed in 1-3 months,
  - 9% in 3-6 months,

  - 5% in 6 months to a year, and
  - 6% in more than one year.

- 17% of patients in France were diagnosed at a family doctor or GP's office,
  - 8% at an emergency department,
  - 35% at a community, local or general hospital,
  - 9% at a major cancer centre[4],
  - 21% at a private clinic (a Global Outlier, compared to 11% globally) and
  - 10% at some other facility.

- According to Table 1, females in France took notably longer to be diagnosed than male patients, with 83% of male patients diagnosed in less than three months compared to 75% of females.

Table 1
Notable Differences for
Time of Diagnosis by Gender

TIME OF DIAGNOSIS	Male	Female	Notable Differences
Less than month	59%	52%	7%
1-3 months	24%	23%	
3-6 months	8%	11%	
6 months-1 year	3%	8%	5%
More than 1 year	6%	6%	
LEGEND			
Most negative			🟥
Most positive			🟩

- As shown in Table 2, younger patients in France took notably longer to be diagnosed with 69% of those 30-45 yrs. diagnosed within the first three months compared to 79% of those aged 46-65 yrs. and 87% of those aged 66+ yrs.

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[4] Including 5% for major cancer centres with kidney cancer specialists

Table 2
Notable Differences for
Time of Diagnosis by Age[5]

TIME OF DIAGNOSIS	30-45 yrs.	46-65 yrs.	66+ yrs.
Less than month	47%	57%	60%
1-3 months	22%	22%	27%
3-6 months	22%	9%	3%
6 months-1 year	3%	6%	4%
More than 1 year	6%	6%	6%
LEGEND			
Most negative			🟥
Most positive			🟩

Patient Knowledge and Understanding

- After initial diagnosis 33% of patients in France were not told their sub-type (38% globally), and
    - 9% had no understanding of their stage (20% globally),
    - 20% had no understanding of their sub-type[6] (a Global Outlier, compared to 43% globally),
    - 3% had no understanding of their treatment options (a Global Outlier, compared to 21% globally),
    - 4% had no understanding of their treatment recommendations (a Global Outlier, compared to 19% globally),
    - 12% had no understanding of the risk of recurrence (a Global Outlier, compared to 28% globally), and
    - 14% had no understanding of their likelihood of survival (a Global Outlier, compared to 25% globally).

- Compared to global results, RCC patients in France had the greatest understanding per patient of their disease upon diagnosis.[7]

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[5] Due to insufficient sample size, data is not available for the under 30 yr. age brackets.

[6] 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.

[7] Further details available in the IKCC Global Report

- As shown in Table 3, at the time of diagnosis,
    - Notably more patients in France with other sub-types had less understanding about their stage compared to clear cell patients (14% for other sub-type versus 9% for clear cell);
    - Clear cell patients had notably less understanding about their likelihood of survival than patients with other sub-types (16% versus 11%); and
    - Both clear cell patients and those with other sub-types had the greatest lack of understanding for sub-type (21% for both), this representing the greatest lack of understanding for any other aspect of the disease listed in the Table.

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

NO UNDERSTANDING	Clear Cell	Other Sub-types	Notable Differences
Stage	**9%**	**14%**	**5%**
Sub-type	**21%**	**21%**	
Treatment options	**3%**	**5%**	
Treatment recommendations	**3%**	**5%**	
Risk of recurrence	**12%**	**15%**	
Likelihood of survival	**16%**	**11%**	**5%**
LEGEND			
Most negative			🟥
Most positive			🟩

- At the time of the survey, 13% of patients in France were still not aware of their sub-type.

- The 87% who were aware reported the following RCC sub-types:
    - Clear cell (66%),
    - Papillary (9%),
    - Chromophobe (5%),
    - Unclassified (1%),
    - XP11 Translocation Type (1%),

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

- At the time of the survey, patients in France had no understanding of the following:
  - Biopsies for kidney cancer (5% a Global Outlier, compared to 20% globally),
  - Surgical options (2% compared to 8% globally).
  - Immunotherapy (12% a Global Outlier, compared to 26% globally),
  - Targeted therapies (14% compared to 23% globally),
  - Radiation therapies (12% a Global Outlier, compared to 29% globally),
  - Ablative therapies (12% compared to 41% globally),
  - Palliative care (23% compared to 33% globally),
  - Active surveillance (11% a Global Outlier, compared to 29% globally),
  - Nutrition/lifestyle (14%),
  - Complementary therapies (30% compared to 39% globally),
  - Guidelines for kidney cancer care (16%), or for
  - Guidelines for kidney cancer follow up (8%, compared to 17% globally).

- Compared to RCC patients globally, patients in France had the greatest understanding per patient about the treatments and guidelines for kidney cancer care.[8]

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[8] Further details are available in the IKCC Global Report.

III. Clinical Trials

Every kidney cancer patient in France 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 France 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.

Compared to global results, the healthcare community in France has been notably more proactive in approaching RCC patients about their possible participation in clinical trials.

89% of patients who had never been approached to participate in a clinical trial reported they would have been amenable particularly if provided with the necessary information to make the decision. This combined with the high degree of likelihood they would agree to participate if asked, and the satisfaction of those who had actually participated, indicates an obvious lost opportunity to improve the quality of care and survivorship of RCC patients through research.

Compared to global results, although considerably more patients were asked to participate in clinical trials in France, the fewest were asked to participate following initial diagnosis. In fact, the vast majority were asked *after surgery, after other treatments, or after they were left with no other treatment options.*

A notable proportion of those patients who either were not or who would not be willing to participate in a clinical trial were either ineligible or were fearful of the outcome of a trial.

Patients who HAD DISCUSSIONS about clinical trials

- According to survey results, clinical trials had not been discussed with 23% of patients in France (33% globally).

- Of those who had discussions about clinical trials, those discussions occurred with:
    - Another patient (7% compared to 12% globally),
    - Doctors (89% compared to 75% globally),
    - Spouses, friends or family (32%),
    - Nurses (6%),
    - Patient organisations (8% a Global Outlier, compared to 19% globally), and
    - Online groups (4% a Global Outlier, compared to 15% globally).

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

- 59% of patients in France had never been asked to participate in a clinical trial (a Global Outlier, compared to 70% globally).

- Of French patients who had never been asked to participate in a clinical trial, 89% said it said it 'fairly likely'[9] they would do so if asked.

- Of the patients in France who said they would be fairly likely[10] to do so, they were being treated at:
    - Community/ local /general hospitals (31% compared to 37% globally),
    - Major cancer centres[11] (46%),
    - 14% at private clinics (6% globally), and
    - 1% at 'other'.

- Of the 89% of French patients who said it would be 'fairly likely' they would participate in a clinical trial:
    - 35% said they would be 'likely' to participate, while
    - 65% 'would require more information to make a decision of whether or not to do so'.

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[9] 'Fairly likely is the combined result of 'Likely' and 'Maybe; would need more information'

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

[11] Including major cancer centres with kidney cancer specialists (33%).

- Of patients in France who said they would need more information before they agreed to participate in a clinical trial, these patients were being treated at:
    - Community/ local /general hospitals (29% compared to 38% globally),
    - Major cancer centres[12] (47%), and
    - Private clinics (13%).

- Patients in France who would be 'fairly likely' to participate in a clinical trial if asked, consisted of:
    - 95% of those with localised RCC (compared to 87% globally),
    - 89% of those with metastatic RCC, and
    - 93% of those with no evidence of the disease or who had been told they were cured.

- 59% of patients in France with clear cell RCC (67% globally) and 66% of those with other sub-types (77% globally) had never been asked to participate in a clinical trial.

- Patients being treated for other sub-types who had never been approached to participate in a clinical trial were being treated at:
    - Community/local or general hospitals (30%),
    - Major cancer centres[13] (48%), and at
    - Private clinics (7%).

Patients who HAD BEEN ASKED to participate in a clinical trial

- Of the patients in France who were asked to participate in a clinical trial:
    - 4% of their initial discussions were with another patient (9% globally),
    - 94% with doctors (compared to 88% globally), and
    - 35% with spouses, family or friends,
    - 8% with nurses (15% globally),
    - 7% with patient organisations (18% globally),
    - 2% with online groups (16% globally), and
    - 2% had no previous discussion with anyone.

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[12] Including major cancer centres with kidney cancer specialists (37%, compared to 30% globally)

[13] Including major cancer centres with kidney cancer specialists (41% compared to 30% globally),

- The option of a clinical trial had first been discussed with:
    - 8% upon diagnosis (a Global Outlier, compared to 24% globally),
    - 44% of patients after surgery (49% globally),
    - 42% after other treatments (a Global Outlier, compared to 21% globally), and
    - 6% who were left with no other treatment options.

- For patients in France who had the option of a clinical trial first discussed with them after surgery:
    - 5% were being treated at community/local or general hospitals (a Global Outlier compared to 18% globally),
    - 84% at major cancer centres[14] (72% globally), and
    - 0% at private clinics.

- When the option of a clinical trial was discussed with patients:
    - 64% understood very well the risks and benefits of participating (a Global Outlier, compared to 47% globally),
    - 30% had at least some understanding (41% globally), and
    - 6% had a very limited understanding (12% globally).

- Of those in France who were asked to participate in a clinical trial, 92% agreed (86% globally).

- Those who agreed to participate did so because:
    - Their doctor recommended it (46% compared to 55% globally),
    - They thought it might offer better care (61%),
    - They wanted a specific type of treatment (16%),
    - It was their only option for treatment (26%),
    - They wanted to help kidney cancer research (46% compared to 39% globally), and
    - Affordability, financial reasons (0% compared to 13% globally).

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[14] Including major cancer centres with kidney cancer specialists (65% compared to 57% globally),

- 83% of patients in France were either ‘very satisfied’ or ‘satisfied’ with the experience (90% globally), and of those:
    - 31% were ‘very satisfied’ (44% globally),
    - 52% ‘satisfied’ (46% globally) and
    - 17% were very dissatisfied (a Global Outlier, compared to 10% globally).

- Those patients who had either never been asked to participate in a clinical trial or who had declined their participation provided the following reasons for their unwillingness to participate:
    - Lack of enough information to make a decision (11% compared to 19% globally),
    - Not eligible for the trial (33% a Global Outlier compared to 21% globally),
    - Distrust of clinical trials (39% compared to 21% globally),
    - Fear of placebo (33% a Global Outlier, compared to 18% globally),
    - Fear of uncertainty (22% a Global Outlier, compared to 26% globally),
    - Extra tests or interventions required (0% a Global Outlier, compared to 18% globally),
    - Geographic distance (11% compared to 16% globally),
    - Affordability, financial costs (0% compared to 7% globally),
    - Not available at my hospital (0% a Global Outlier, compared to 14% globally),
    - Toxicity of treatment (22%), and
    - Other (11% compared to 16% globally).

IV. Quality of Care

Kidney cancer has a profound effect on the lives of patients in France as evidenced by the impact of both physical conditions and psychosocial issues, as well as the barriers standing in their way to receiving quality care.

There is strong evidence to suggest that RCC patients in France are choosing to 'suffer in silence' from the effects of their disease, not reaching out to their healthcare teams for the support they need to improve the quality of their lives. This is particularly relevant given the evidence in this report suggesting that 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 more heavily impacted patient sub groups 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 France to advocate for change and to provide support for patients who struggle with barriers to quality care. Compared to global results, patients in France were impacted considerably less by barriers to receiving quality care.

Compared to patients globally, RCC patients in France were similar in the degree to which they experienced physical conditions, with fatigue reported as the greatest factor affecting their physical well-being. Patients were notably better off than patients globally for a number of psychosocial issues, with disease related anxiety and the fear of recurrence reported as having the greatest impacts.

Although male and female RCC patients have a similar biological experience with kidney cancer, female patients in France were more notably affected than male patients from a number of psychosocial issues particularly related to anxiety. Males and females experienced very different physical conditions.

Overall, patients diagnosed 2014 and later in France were more negatively affected by physical conditions than those diagnosed prior to that time. Similarly, patients were affected by a number of psychosocial issues, which were reported to have been notably worse for those diagnosed in more recent years, suggesting that psychosocial issues could be worsening over time.

Surprisingly, patients in France with localised RCC, or who had no evidence of the disease, or who had been told they were cured, were notably more affected by a number of physical conditions and psychosocial issues than metastatic patients.

Despite the fact that 97% of patients in France were impacted by psychosocial issues, and a high percentage were finding their doctors to be helpful when they did reach out, as many as one third were not communicating their emotional issues to their healthcare team.

It is notable that male patients and those over 66 yrs. in France were the most open with their doctors compared to patients in other countries.

RCC patients in France experienced the fewest number of barriers per patient of all patients in other countries, and younger patients, and patients with rarer sub-types were affected notably less overall.

Treatment for Kidney Cancer

- According to survey results, 10% of French patients had not had any treatment for their kidney cancer after their first diagnosis (a Global Outlier compared to 4% globally).

- At the time of the survey, 11% of patients in France had not been receiving any treatments at all.

- As shown in Table 4, for their first treatment,
    - 33% received them from community/local or general hospitals (47% globally),
    - 35% at major cancer centres[15], and
    - 21% from private clinics (a Global Outlier, compared to 7% globally.

- Of those patients in France who had been receiving treatments since that time:
    - 21% had been receiving them from community/local or general hospitals (31% globally),
    - 55% from major cancer centres[16], and
    - 11% from private clinics.

- As can be seen in Table 4, there was a notable migration of patients initially treated at community/local or general hospitals and private clinics to major cancer centres, as evidenced by a decline of 20% and a corresponding increase of major cancer centres.

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[15] Including major cancer centres with kidney cancer specialists (25%)

[16] Including major cancer centres with kidney cancer specialists (43% compared to 36% globally)

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

PLACE OF TREATMENT	First Treatment	Subsequent Treatments	Notable Differences
Community/local/general hospitals	**31%**	**21%**	**-10%**
Major cancer centres	**35%**	**55%**	**20%**
Private clinics	**21%**	**11%**	**-10%**

Physical Conditions

- As can be seen in Table 5, 6% of French patients had not been impacted by any conditions affecting their physical well-being since initial diagnosis.

- Of those who were impacted, fatigue was the condition that affected them the most.

- Patients in France were considerably more impacted than patients globally by cramps, and considerably less by itching.

- They were more notably affected by:
  - Fatigue,
  - Bowel changes, and by
  - Changes in sexual function.

- They were less notably impacted by nausea and vomiting.

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

PHYSICAL CONDITIONS	Global	France	Notable Differences
NOT AFFECTED	8%	6%	
Fatigue	66%	72%	6%
Trouble concentrating	24%	23%	
Mucositis/mouth ulcers	17%	15%	
Muscle weakness	32%	31%	
Pain related to surgery	29%	28%	
Bowel changes	33%	41%	8%
Loss of appetite	25%	20%	5%
Changes in taste and smell	25%	26%	
Sleeplessness	31%	29%	
Itching	17%	12%	5%
Hair loss	13%	10%	
Change of hair colour	17%	14%	
Memory loss	13%	12%	
Changes in sexual function	15%	20%	5%
Aching joints	22%	18%	
Sore feet and hands	23%	23%	
Weight loss	24%	24%	
Cramps	11%	19%	8%
Fluid retention	12%	10%	
Skin reactions	17%	19%	
Nausea and vomiting	22%	17%	5%

LEGEND	
Negative	🟥
Positive	🟩

- As can be seen in Table 6, males were more notably affected than females by:
  - Change of hair colour,
  - Sore feet and hands,
  - Bowel changes,
  - Loss of appetite, and by
  - Weight loss.

- Females were more notably affected than males by:
    - Fatigue,
    - Trouble concentrating,
    - Sleeplessness,
    - Hair loss,
    - Memory loss, and by
    - Aching joints.

Table 6
Notable Differences in France for
Physical Conditions by Gender

PHYSICAL CONDITION	Males	Females	Notable Differences
NOT AFFECTED	5%	9%	
Fatigue	69%	78%	9%
Trouble concentrating	18%	30%	12%
Mucositis/mouth ulcers	14%	15%	
Muscle weakness	30%	33%	
Pain related to surgery	29%	26%	
Bowel changes	44%	36%	8%
Loss of appetite	25%	15%	10%
Changes in taste and smell	27%	25%	
Sleeplessness	25%	35%	10%
Itching	11%	15%	
Hair loss	5%	17%	12%
Change of hair colour	16%	11%	5%
Memory loss	10%	16%	6%
Changes in sexual function	21%	20%	
Aching joints	16%	21%	5%
Sore feet and hands	25%	19%	6%
Weight loss	26%	20%	6%
Cramps	19%	19%	
Fluid retention	10%	10%	
Skin reactions	21%	17%	
Nausea and vomiting	19%	14%	5%
LEGEND			
Negative (white font = Global Outlier)			🟥
Positive (enlarged font= Global Outlier)			🟩

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

- For example, in France both male and female patients were considerably worse off with cramps than male and female patients in other countries.

Table 7
Global Outliers for France
Physical Conditions by Gender

PHYSICAL CONDITION	Males	Females
Cramps	19%	19%
Changes in sexual function		20%
Itching		15%

LEGEND	
Negative Global Outlier for France	🟥
Positive Global Outlier for France	🟩

- As Table 8 shows, patients diagnosed 2014 and later were notably more negatively affected than patients diagnosed prior to 2014 by:
  - Fatigue,
  - Pain related to surgery,
  - Sleeplessness, and by
  - Aching joints.

- Patients diagnosed prior to 2014 were notably more affected by:
  - Bowel changes,
  - Changes in taste and smell,
  - Sore feet and hands,
  - Weight loss, and by
  - Cramps.

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

PHYSICAL CONDITION	Prior to 2014	2014 and Later	Notable Differences
NOT AFFECTED	10%	1%	9%
Fatigue	70%	76%	6%
Trouble concentrating	22%	25%	
Mucositis/mouth ulcers	15%	14%	
Muscle weakness	30%	34%	
Pain related to surgery	24%	34%	10%
Bowel changes	45%	35%	10%
Loss of appetite	20%	21%	
Changes in taste and smell	30%	20%	10%
Sleeplessness	24%	36%	12%
Itching	13%	12%	
Hair loss	10%	12%	
Change of hair colour	14%	14%	
Memory loss	11%	14%	
Changes in sexual function	22%	18%	
Aching joints	14%	24%	10%
Sore feet and hands	26%	19%	7%
Weight loss	26%	20%	6%
Cramps	22%	14%	8%
Fluid retention	10%	9%	
Skin reactions	20%	18%	
Nausea and vomiting	18%	16%	

LEGEND	
Most negative	🟥
Most positive	🟩

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

- For example, French patients diagnosed in 2014 and later were considerably better off for itching than patients in other countries diagnosed at that time.

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

PHYSICAL CONDITION	Prior to 2014	2014 and Later
NOT AFFECTED		1%
Cramps	22%	
Itching		12%

LEGEND	
Negative Global Outlier for France	🟥
Positive Global Outlier for France	🟩

- As shown in Table 10, metastatic RCC patients were more notably affected by physical conditions than patients with localised RCC, or who had no evidence of the disease, or who had been told they were cured.

Table 10
Notable Differences in France for Physical Conditions by Stage

PHYSICAL CONDITION	Localised RCC	Metastatic RCC	No Evidence/ cured
NOT AFFECTED	🟥 3%	🟥 5%	🟩 12%
Fatigue	🟩 55%	🟥 82%	66%
Trouble concentrating	🟩 16%	🟥 25%	🟥 26%
Mucositis/mouth ulcers	🟥 16%	🟥 20%	🟩 2%
Muscle weakness	🟩 23%	🟥 41%	🟩 16%
Pain related to surgery	29%	🟩 20%	🟥 36%
Bowel changes	🟩 29%	🟥 60%	🟩 28%
Loss of appetite	🟥 19%	🟥 25%	🟩 8%
Changes in taste and smell	🟥 26%	🟥 39%	🟩 4%
Sleeplessness	🟩 23%	🟥 31%	🟥 32%
Itching	🟩 10%	🟥 20%	🟩 6%
Hair loss	10%	10%	6%
Change of hair colour	10%	🟥 25%	🟩 4%
Memory loss	🟩 6%	🟥 16%	🟥 16%
Changes in sexual function	10%	🟥 33%	🟩 6%
Aching joints	🟩 6%	🟥 22%	🟩 10%
Sore feet and hands	🟩 10%	🟥 34%	🟩 10%
Weight loss	🟥 19%	🟥 29%	🟩 8%
Cramps	🟥 16%	🟥 29%	🟩 8%
Fluid retention	🟥 13%	8%	🟩 2%
Skin reactions	🟥 23%	🟥 30%	🟩 6%
Nausea and vomiting	🟥 16%	🟥 22%	🟩 4%

LEGEND	
Most negative	🟥
Most positive	🟩

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

- For example, compared to patients globally, overall, patients with metastatic RCC in France were considerably better off.

Table 11
Global Outliers for France
Conditions Affecting Physical Well-being by Stage

PHYSICAL CONDITION	Localised RCC	Metastatic RCC	No Evidence/ cured
NOT AFFECTED		5%	
Bowel changes	29%		28%
Hair loss		10%	
Cramps		29%	
Fatigue			66%
Mucositis/mouth ulcers			2%
LEGEND			
Negative Global Outlier for France			🟥
Positive Global Outlier for France			🟩

Psychosocial Issues

- As can be seen in Table 12, 3% of French patients had not had their sense of emotional well-being impacted by psychosocial issues since initial diagnosis.

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

- Compared to global results, patients in France were affected considerably less by:
  - Difficulty on the job or in school, and by
  - Problems getting life/health insurance.

- They were less notably affected by:
  - Depression,
  - Stress related to financial issues,
  - Loss/reduction in employment, and by
  - Difficulty navigating the healthcare system.

- They were affected notably more by sexuality.

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

PSYCHOSOCIAL ISSUE	Global	France	Notable Differences
NOT AFFECTED	4%	3%	
General anxiety	31%	27%	
Disease-related anxiety	60%	63%	
Fear of dying	44%	42%	
Fear of recurrence	50%	53%	
Depression	27%	15%	12%
Isolation	16%	13%	
Changes in relationships	28%	29%	
Difficulty on the job or in school	19%	12%	7%
Stress related to financial issues	28%	11%	17%
Loss or reduction in employment	20%	12%	8%
Difficulty navigating the healthcare system	14%	7%	7%
Problems getting life or health insurance	13%	4%	9%
Concerns about body image/physical appearance	22%	23%	
Relationships with friends/others	18%	17%	
Sexuality	14%	22%	8%
LEGEND			
Negative (white font = Global Outlier)			🟥
Positive (enlarged font= Global Outlier)			🟩

- According to Table 13, females in France were notably more affected than females overall for psychosocial issues affecting their emotional well-being.

- Females were affected notably more than males by:
    - General anxiety,
    - Disease-related anxiety,
    - Fear of dying,
    - Fear of recurrence,
    - Depression,
    - Isolation,
    - Loss/reduction in employment, and by
    - Relationships, with friends/other.

Table 13
Notable Differences in France for Psychosocial Issues by Gender

PSYCHOSOCIAL ISSUE	Males	Females	Notable Differences
NOT AFFECTED	5%	0%	5%
General anxiety	23%	32%	9%
Disease-related anxiety	60%	67%	7%
Fear of dying	37%	48%	11%
Fear of recurrence	48%	57%	9%
Depression	10%	24%	14%
Isolation	9%	19%	10%
Changes in relationships	29%	30%	
Difficulty on the job or in school	13%	10%	
Stress related to financial issues	10%	12%	
Loss or reduction in employment	10%	15%	5%
Difficulty navigating the healthcare system	6%	8%	
Problems getting life or health insurance	3%	4%	
Concerns about body image/physical appearance	22%	24%	
Relationships with friends/others	14%	20%	6%
Sexuality	22%	21%	

LEGEND	
Most negative	🟥
Most positive	🟩

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

- For example, females were considerably worse off in dealing with their sexuality than female patients in other countries.

Table 14
Global Outliers for France
Psychosocial Issues by Gender

PSYCHOSOCIAL ISSUE	Males	Females
Difficulty navigating the healthcare system	6%	
Problems getting life/health insurance	3%	
Sexuality		21%
LEGEND		
Negative Global Outlier for France		🟥
Positive Global Outlier for France		🟩

- As shown in Table 15, patients who were diagnosed in 2014 and later were more notably affected than those diagnosed prior to 2014 by:
    - General anxiety,
    - Disease-related anxiety,
    - Fear of dying,
    - Fear of recurrence,
    - Changes in relationships,
    - Stress related to financial issues, and by
    - Loss/reduction in employment.

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

PSYCHOSOCIAL ISSUE	Prior to 2014	2014 and Later	Notable Differences
NOT AFFECTED	4%	1%	
General anxiety	23%	33%	10%
Disease-related anxiety	61%	66%	5%
Fear of dying	37%	49%	12%
Fear of recurrence	50%	56%	6%
Depression	16%	15%	
Isolation	11%	15%	
Changes in relationships	26%	34%	8%
Difficulty on the job or in school	13%	9%	
Stress related to financial issues	5%	19%	14%
Loss or reduction in employment	10%	15%	5%
Difficulty navigating the healthcare system	5%	9%	
Problems getting life or health insurance	2%	6%	
Concerns about body image/physical appearance	22%	25%	
Relationships with friends/others	17%	16%	
Sexuality	23%	21%	

LEGEND	
Most negative	🟥
Most positive	🟩

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

- For example, French patients diagnosed in 2014 and later were considerably better off dealing with depression and stress related to financial issues than patients in other countries.

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

PSYCHOSOCIAL ISSUE	Prior to 2014	2014 and Later
Difficulty on the job or in school	13%	
Loss/reduction in employment	10%	
Difficulty navigating the healthcare system	5%	
Depression		15%
Stress related to financial issues		19%

LEGEND	
Negative Global Outlier for France	🟥
Positive Global Outlier for France	🟩

- Table 17 details specific psychosocial issues affecting patients by stage.
- For example, metastatic RCC patients were less notably affected overall by psychosocial issues than patients with localised RCC.

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

PSYCHOSOCIAL ISSUE	Localised RCC	Metastatic RCC	No Evidence/ Cured
NOT AFFECTED	🟥 0%	🟩 6%	2%
General anxiety	🟥 41%	🟩 20%	🟥 35%
Disease-related anxiety	63%	🟥 71%	🟩 56%
Fear of dying	🟥 50%	43%	🟩 35%
Fear of recurrence	53%	🟩 41%	🟥 65%
Depression	🟩 13%	🟩 12%	🟥 21%
Isolation	13%	16%	13%
Changes in relationships	🟥 34%	33%	🟩 29%
Difficulty on the job or in school	🟥 13%	🟥 16%	🟩 8%
Stress related to financial issues	🟩 9%	🟩 10%	🟥 15%
Loss or reduction in employment	🟩 6%	🟥 13%	🟥 12%
Difficulty navigating the healthcare system	3%	4%	6%
Problems getting life or health insurance	🟥 6%	🟩 1%	🟥 6%
Concerns about body image/physical appearance	22%	🟥 29%	🟩 13%
Relationships with friends/others	🟩 13%	🟥 23%	🟩 15%
Sexuality	🟩 9%	🟥 29%	17%

LEGEND	
Most negative	🟥
Most positive	🟩

- Table 18 illustrates Global Outliers for psychosocial issues affecting patient's emotional well-being in France by stage.

- For example, those with no evidence of the disease, or who had been told they were cured in France were considerably worse off for the fear of recurrence than patients in other countries.

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[17] Due to insufficient sample size, data is not available for patients with localised RCC

Table 18
Global Outliers for France
Psychosocial Issues by Stage

PSYCHOSOCIAL ISSUE	Localised RCC	Metastatic RCC	No Evidence/ cured
Depression	13%		65%
Stress related to financial issues	9%		
Fear of recurrence		41%	65%
Difficulty on the job or in school		16%	8%
Stress related to financial issues		10%	
Difficulty navigating the healthcare system		4%	
Changes in relationships			29%
LEGEND			
Negative Global Outlier for France			🟥
Positive Global Outlier for France			🟩

Patient Timeline- Most Difficult Times

- According to Table 19, French patients experienced the most difficult times:
    - During the process of diagnosis,
    - Surgery and recovery afterwards, and
    - Waiting for surgery or scan results.

- Compared to patients globally, they were more notably affected by diagnosis of recurrence.

- They were less notably affected by the surveillance period.

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

MOST DIFFICULT TIME	Global	France	Notable Differences
NOT AFFECTED	2%	0%	
During the process of diagnosis	51%	49%	
Surveillance period	19%	14%	5%
Surgery & recovery afterwards	38%	39%	
Follow up scans	17%	19%	
Waiting for surgery or scan results	37%	38%	
Diagnosis of recurrence	21%	26%	5%
Treatment for recurrence	10%	10%	
Diagnosis of further disease progression	23%	25%	
Dealing with side effects of treatment	29%	32%	
Transition to palliative care	4%	2%	
Long term adjustment, survivorship	12%	8%	

LEGEND	
Negative (white font = Global Outlier)	🟥
Positive (enlarged font= Global Outlier)	🟩

- As shown in Table 20, males in France were more notably affected than females by the side effects of treatment.

- Female patients were considerably worse off for diagnosis for recurrence than male patients in other countries (28% a Global Outlier, compared to 20% globally).

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

MOST DIFFICULT TIME	Males	Females	Notable Differences
NOT AFFECTED	1%	0%	
During the process of diagnosis	50%	48%	
Surveillance period	13%	16%	
Surgery and recovery afterwards	37%	39%	
Follow up scans	20%	18%	
Waiting for surgery or scan results	37%	39%	
Diagnosis of recurrence	25%	28%	
Treatment for recurrence	8%	12%	
Diagnosis of further disease progression	26%	24%	
Dealing with side effects of treatment	34%	29%	5%
Transition to palliative care	2%	2%	
Long term adjustment, survivorship	7%	10%	

LEGEND	
Negative (white font = Global Outlier)	🟥
Positive (enlarged font= Global Outlier)	🟩

Communication and Support from Healthcare Professionals

- Of those patients in France who experienced psychosocial issues 65% (50% globally) said they communicated the issues to a healthcare professional, while 35% had not done so (50% globally).

- In France:
  - 57% were very open and told the doctor everything in great detail (47% globally),
  - 24% shared some of their issues, but not to the full extent (31% globally),
  - 12% held back some details and minimized their symptoms and side effects, or chose not to communicate their issues at all, and
  - 8% had not had the opportunity to communicate their issues at all.

- Of patients in France who chose to tell the doctor everything in great detail about their psychosocial issues this was the case for:
    - 59% of male patients (a Global Outlier, compared to 52% globally) and 55% of female patients
    - 41% of those[18] aged 30-45 yrs.,
    - 55% of those 46-65 yrs. (49% globally), and
    - 67% of those 66+ yrs. (a Global Outlier, compared to 54% globally).

- For those who communicated their issues, 88% of patients found their doctors to be helpful, while this had not been the case for the remaining 12%.

- Of these patients, 50% found their doctors to be very helpful, and 38% found them to be somewhat helpful.

Barriers to Receiving Quality Care

- Patients in France had the following types of healthcare coverage:
    - Government healthcare (97% compared to 73% globally),
    - Private insurance (30%, compared to 39% globally),
    - Self-coverage (7%, compared to 14% globally), and
    - Family coverage (0%, compared to 6% globally).

- As Table 21 shows, patients in France were affected most by wait times to treatment, and by a lack of personal support.

- Compared to patients in other countries, they were considerably better off overall for barriers to receiving quality care, and for managing their career and caregiver role during treatment.

- They were impacted less notably by a number of other barriers to quality care as illustrated in Table 21.

- Patients in France experienced the least number of barriers to receiving quality care per patient compared to patients in other countries[19].

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[18] Due to insufficient sample sizes, data was not reported for the Under 18-29 age bracket.

[19] Further details are available in the IKCC Global Report.

Table 21
Notable Differences between France and Global Results for Barriers to Receiving Quality Care

BARRIER TO RECEIVING QUALITY CARE	Global	France	Notable Differences
NOT AFFECTED	39%	64%	25%
Lack of affordability, cost of treatment	21%	2%	19%
Lack of access to treatment centre (travel)	13%	5%	8%
Inability to understand the treatment	6%	0%	6%
Lack of access to up-to-date treatment/equipment	14%	4%	10%
Wait time to treatment was longer than necessary	18%	9%	9%
Lack of personal support	14%	8%	6%
No specialty doctor available locally	13%	7%	6%
Difficulty managing career/caregiver role while in treatment	9%	1%	8%
Fear of discrimination by my employer/ friends/ family	9%	6%	
No available treatments	5%	5%	

LEGEND	
Negative (white font = Global Outlier)	🟥
Positive (enlarged font= Global Outlier)	🟩

- According to Table 22, older patients (66+ yrs.) in France were affected overall by notably fewer barriers to receiving quality care than younger age groups.

Table 22
Notable Differences in France for
Barriers to Receiving Quality Care by Age[20]

BARRIER TO RECEIVING QUALITY CARE	30-45 yrs.	46-65 yrs.	66+ yrs.
NOT AFFECTED	🟥 59%	🟥 59%	🟩 75%
Lack of affordability, cost of treatment	🟩 0%	1%	🟥 5%
Lack of access to treatment centre (travel)	3%	7%	3%
Inability to understand the treatment	0%	0%	0%
Lack of access to up-to-date treatment/equipment	7%	4%	5%
Wait time to treatment was longer than necessary	10%	9%	8%
Lack of personal support	🟥 14%	🟥 9%	🟩 3%
No specialty doctor available locally	🟩 3%	🟥 11%	🟩 2%
Difficulty managing career/caregiver role while in treatment	0%	1%	3%
Fear of discrimination by my employer/ friends/ family	🟥 14%	🟩 7%	🟩 2%
No available treatments	🟥 10%	6%	🟩 0%

LEGEND	
Most negative	🟥
Most positive	🟩

- Table 23 shows Global Outliers for barriers to receiving quality care in France by age.

- For example, French patients aged 46-65 yrs. were considerably better off for their lack of access to the most up to date treatment and equipment than patients of a similar age in other countries.

- French patients 30-45 yrs. and those aged 66+ yrs. experienced the least number of barriers to receiving quality care per patient than patients of the same ages in other countries[21].

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[20] Due to insufficient sample size, data is not reported for under 30 yr. age bracket.

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

Table 23
Global Outliers for France
Barriers to Receiving Quality Care by Age

BARRIER TO RECEIVING QUALITY CARE	30-45 yrs.	46-65 yrs.	66+ yrs.
NOT AFFECTED	59%		
Lack of access to up to date treatment	7%	4%	
No specialty doctor available locally	3%		
Difficulty managing career/ caregiver role while in treatment	0%		
Lack of personal support			3%
LEGEND			
Negative Global Outlier for France			🟥
Positive Global Outlier for France			🟩

- As Table 24 indicates, males were notably more affected by lack of access to the most up to date treatment and equipment than females, while females were more notably affected by a lack of personal support than males.

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

BARRIER TO RECEIVING QUALITY CARE	Male	Female	Notable Differences
NOT AFFECTED	65%	63%	
Lack of affordability, cost of treatment	3%	0%	
Lack of access to treatment centre (travel)	5%	6%	
Inability to understand the treatment	0%	0%	
Lack of access to up-to-date treatment/equipment	6%	1%	5%
Wait time to treatment was longer than necessary	8%	10%	
Lack of personal support	5%	11%	6%
No specialty doctor available locally	6%	6%	
Difficulty managing career/caregiver role while in treatment	0%	4%	
Fear of discrimination by my employer/ friends/ family	6%	8%	
No available treatments	5%	4%	
LEGEND			
Most negative			🟥
Most positive			🟩

- Table 25 shows Global Outliers for barriers to receiving quality care in France by gender.

- For example, compared to patients globally, male patients in France were considerably less affected by difficulty managing their caregiver role than male patients globally.

- Both male and female patients in France experienced the fewest number of barriers to receiving quality care per patient compared to male and female patients in other countries[22].

Table 25
Global Outliers for France
Barriers to Receiving Quality Care by Gender

BARRIERS TO RECEIVING QUALITY CARE	Males	Females
Difficulty managing career/caregiver role while in treatment	0%	
Lack of access to up to date treatment/equipment		1%
LEGEND		
Negative Global Outlier for France		🟥
Positive Global Outlier for France		🟩

- As shown in Table 26 patients with other sub-types were affected notably more than patients with clear cell RCC by:
  - Lack of access to the most up to date treatment/equipment,
  - Lack of available treatments, and by
  - Lack of personal support.

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

Table 26
Notable Differences in France for Barriers to Receiving Quality Care by Sub-Type

BARRIER TO RECEIVING QUALITY CARE	Clear Cell	Other sub-types	Notable Differences
NOT AFFECTED	65%	62%	
Lack of affordability, cost of treatment	3%	0%	
Lack of access to treatment centre (travel)	6%	3%	
Inability to understand the treatment	0%	0%	
Lack of access to up-to-date treatment/equipment	4%	10%	6%
Wait time to treatment was longer than necessary	8%	10%	
Lack of personal support	7%	13%	6%
No specialty doctor available locally	7%	8%	
Difficulty managing career/caregiver role while in treatment	1%	0%	
Fear of discrimination by my employer/ friends/ family	7%	5%	
No available treatments	4%	10%	6%
LEGEND			
Most negative			🟥
Most positive			🟩

- Table 27 shows Global Outliers for barriers to receiving quality care in France by sub-type.

- Clear cell patients and those with other sub-types in France were affected considerably less in managing their caregiver role than patients in other countries.

- Patients with clear cell RCC in France experienced among the least number of barriers to receiving quality care per patient than patients with clear cell in other countries[23].

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

Table 27
Global Outliers for France
Barriers to Receiving Quality Care by Sub-type

BARRIERS TO CARE	Clear Cell	Other sub-types
NOT AFFECTED		62%
Difficulty managing career/caregiver role while in treatment	1%	0%
LEGEND		
Negative Global Outlier for France		🟥
Positive Global Outlier for France		🟩

V. Opportunities to Improve Care

There is an opportunity for IKCC and its Affiliate Organisations to improve survivorship of patients in France by empowering patients through education to advocate for regular surveillance despite gender, age or stage, particularly for middle aged patients and those lacking an understanding of kidney cancer guidelines.

Surveillance

- At the time of the survey, patients in France were in the following stages of their RCC:
  - 9% were in Stage 1 or 2,
  - 7% were in Stage 3,
  - 42% were in Stage 4,
  - 7% had no evidence of the disease (19% globally),
  - 18% had been told they were cured (10% globally), and
  - 10% had died (4% globally).

- Their last follow up scan had occurred:
  - Less than one year ago (84%),
  - 1-3 years ago (8%), and
  - More than 3 years ago (6%).

- Of those who had received a follow up scan more than three years ago:
  - 8% were being treated at a community, local or general hospital,
  - 15% at a major cancer centre,
  - 0% at a private clinic, and
  - 77% were not being treated anywhere.

- Most recent follow up scans had occurred more than three years ago for:
  - 0% of those in Stage 1 or 2,
  - 7% of those in Stage 3,
  - 1% of those in Stage 4,
  - 8% of those who had no evidence of the disease, or had been told they were cured,
  - 42% of those who had died,

- 3% of those aged 30-45[24] yrs.,
- 7% of those aged 46-65 (a Global Outlier, compared to 4% globally),
- 6% of those aged 66+ yrs.,

- 5% of males,
- 8% of females,

- 4% of those with no understanding of kidney cancer guidelines, and
- 13% of those with no understanding of the guidelines for kidney cancer follow up (a Global Outlier, compared to 5% globally).

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[24] Due to insufficient data, results are not reported for the under 30 yr. age brackets

VI. Shared decision making

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

Patients in France fall in line with the global average for those whose treatment plans were decided for them solely by their doctors. There was lack of shared decision making particularly for patients being treated at major cancer centres, for those under 66 yrs., and for those in later stages of the disease.

- 27% of patients in France had not been engaged at all in their treatment plans, in that their doctor had solely decided their treatment plans for them.

- Of those patients who were involved in their treatment decision:
    - 9% made the decision by themselves,
    - 55% made a joint decision with their doctors, and
    - 8% were asked for input from their doctors.

- The following helped French patients with their treatment plans:
    - Partner/spouse (70% compared to 56% globally),
    - Parents (13%),
    - Children (29% a Global Outlier, compared to 21% globally),
    - Friends/other family members (26% compared to 20% globally),
    - Local family doctor (38% a Global Outlier, compared to 22% globally), and
    - A patient organisation (4%, a Global Outlier, compared to 12% globally).

- 16% of patients made the decision by themselves, and for 3%, the decision rested on their personal financial situation.

- Of those patients in France where their treatment plans were decided for them by their doctors:
  - 19% were being treated in community centres/local or general hospitals (34% globally),
  - 47% at major cancer centres[25], and
  - 18% at private clinics (9% globally).

- Treatment decisions were decided by the doctor for:[26]
  - 28% of those aged 30-45 yrs.,
  - 30% of those aged 46-65 yrs.,
  - 18% of those aged 66+ yrs. (27% globally).

  - 11% of those in Stage 1 or 2 (25% globally),
  - 29% of those in Stage 3 (20% globally),
  - 30% of those in Stage 4,
  - 29% of those who had no evidence of the disease, or who were told they were cured,
  - 30% of those who had died.

  - 25% of males,
  - 29% of females,

  - 27% if those diagnosed prior to 2016, and
  - 25% of those diagnosed 2016 and later.

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[25] Including major cancer centres with kidney cancer specialists (33%),

[26] Due to insufficient sample size, data is not reported for the under 30 age brackets.

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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