



2018 IKCC PATIENT SURVEY

-Canada-

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International Kidney Cancer Coalition
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Preface

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

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

Perception Insight (PI)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 $\leq 5\%$ or $\geq 5\%$.

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

3. Order of Magnitude

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

Country vs. Global Results

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

INTRODUCTION

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

Kidney cancer (renal cell carcinoma or RCC) is the seventh most common histological type of cancer in the Western world³ and has shown a sustained increase in its global prevalence thereby presenting an increasing burden to health systems, governments, and most of all, to individual patients and their families. Although therapies have improved for both early-stage and late-stage RCC patients, little is known about the variations in the patient experience and best practices among countries.

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

Knowledge and Understanding

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

Clinical Trials

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

² www.ikcc.org

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

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

Quality of Care

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

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;
- 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 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 where there is evidence of physician directed care.

SURVEY RESULTS- Canada

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:

- Canada had 246 respondents, or 12% of the global total.
- 85% of those responding to the survey were kidney cancer patients (71% globally) while the remaining 15% defined themselves as a caregiver, family member or friend of the patient (29% globally).
- 55% of respondents were males and 45% were females.
- Survey respondents had the following age profile:
 - Under 18 (0%),
 - 18-29 (1%),
 - 30-45 (10% compared to 20% globally),
 - 46-65 (52% compared to 57% globally), and
 - 66+ (37% compared to 20% globally).
- Survey respondents were in the following stages of kidney cancer:
 - Localised kidney cancer (13% compared to 23% globally),
 - Metastatic (45%), and
 - No evidence/told they were cured (43% 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 Canada 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 favorable outcome.

Upon diagnosis, nearly one third of RCC patients in Canada were not told their sub-type, a foundational piece of information of which all RCC patients should be aware.

Younger patients (30-45 yrs.) and female patients in Canada took the longest to be correctly diagnosed. 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.

However, when compared to global averages, Canadian patients' knowledge about certain RCC treatments was generally greater for certain treatments.

Year of Diagnosis

- Canadian patients who responded to this survey had been diagnosed in the following years:
 - 10% prior to 2005,
 - 2% in 2005,
 - 4% in 2006,
 - 2% in 2007,
 - 3% in 2008,
 - 1% in 2009,
 - 5% in 2010,
 - 5% in 2011,
 - 5% in 2012,
 - 8% in 2013,
 - 9% in 2014,
 - 6% in 2015,
 - 10% in 2016,
 - 17% in 2017, and
 - 14% in 2018.

Success of Timely Diagnosis

- Patients in Canada were in the following stages of their kidney cancer when they were first diagnosed:
 - 59% were in Stages 1 or 2, still only within the kidney (53% globally),
 - 15% were in Stage 3, cancer was still locally advanced (20% globally), and
 - 25% were in Stage 4, the cancer had spread to distant sites (metastatic).

- Following their first visit to the doctor, 51% of Canadian patients were correctly diagnosed in less than a month, while
 - 25% were diagnosed in 1-3 months,
 - 11% were diagnosed in 3-6 months,
 - 7% were diagnosed in 6 months to a year, and
 - 6% were diagnosed in more than one year.

- 34% of patients in Canada were diagnosed at a family doctor or GP's office (20% globally),
 - 17% at an emergency department (12% globally),
 - 23% at a community, local or general hospital (37% globally),
 - 10% at a major cancer centre⁴,
 - 4% at a private clinic (11% globally) and
 - 12% at some other facility (7% globally).
- According to Table 1, females in Canada took notably longer to be diagnosed than male patients, with 85% of male patients diagnosed in less than three months compared to 63% of females (82% of males and 73% of females globally).
- 28% of females in Canada were diagnosed in three months to a year (a Global Outlier, compared to 19% globally) compared to 11% of males.

Table 1
Notable Differences for
Time of Diagnosis by Gender

TIME OF DIAGNOSIS	Male	Female	Notable Differences
Less than month	58%	41%	17%
1-3 months	27%	22%	5%
3-6 months	7%	17%	10%
6 months-1 year	4%	11%	7%
More than 1 year	5%	9%	
LEGEND			
Most negative			
Most positive			

⁴ Including 8% for major cancer centres with kidney cancer specialists

- As shown in Table 2, younger patients in Canada took notably longer to be diagnosed with 54% of those 30-45 yrs. diagnosed within the first 3 months compared to 73% aged 46-65 yrs. and 81% aged 66+ yrs.

Table 2
Notable Differences for
Time of Diagnosis by Age⁵

TIME OF DIAGNOSIS	30-45 yrs.	46-65 yrs.	66+ yrs.
Less than month	18%	59%	47%
1-3 months	36%	14%	37%
3-6 months	27%	14%	5%
6 months-1 year	9%	7%	6%
More than 1 year	9%	6%	6%
LEGEND			
Most negative			
Most positive			

Patient Knowledge and Understanding

- After their initial diagnosis, 31% of patients were not told their sub-type (38% globally), and
 - 15% had no understanding of their stage (20% globally),
 - 42% had no understanding of their sub-type⁶,
 - 15% had no understanding of their treatment options (21% globally),
 - 13% had no understanding of their treatment recommendations (19% globally),
 - 27% had no understanding of the risk of recurrence, and
 - 22% had no understanding of their likelihood of survival.

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

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.

- As shown in Table 3, at the time of diagnosis:
 - There were no notable differences between clear cell patients and those with other sub-types for their understanding about various aspects of their disease; and
 - Both clear cell patients and those with other sub-types had the greatest lack of understanding for sub-type (42% of those with clear cell and 40% of those with other sub-types).

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

NO UNDERSTANDING	Clear Cell	Other Sub-types	Notable Differences
Stage	16%	15%	
Sub-type	42%	40%	
Treatment options	15%	16%	
Treatment recommendations	14%	13%	
Risk of recurrence	27%	30%	
Likelihood of survival	25%	22%	
LEGEND			
Most negative			
Most positive			

- At the time of the survey, 14% of patients in Canada were still not aware of their sub-type.
- The 86% who were aware reported the following RCC sub-types:
 - Clear cell (63%),
 - Papillary (7%),
 - Chromophobe (4%),
 - Unclassified (4%),
 - XP11 Translocation Type (0%),
 - VHL (0%),
 - Renal Medullary (0%),
 - Collecting Duct (0%),
 - Transitional Cell Carcinoma (0%),
 - Renal Sarcoma (0%),
 - Wilms Tumour (0%),

- Benign Tumour (1%),
- Other (6%).

- At the time of the survey, patients in Canada also had no understanding of the following:
 - Biopsies for kidney cancer (13% compared to 20% globally),
 - Surgical options (5%),
 - Immunotherapy (27%),
 - Targeted therapies (27%),
 - Radiation therapies (29%),
 - Ablative therapies (57% compared to 41% globally),
 - Palliative care (27% compared to 33% globally),
 - Active surveillance (23% compared to 29% globally),
 - Nutrition/lifestyle (12%),
 - Complementary therapies (37%),
 - Guidelines for kidney cancer care (17%), or for
 - Guidelines for kidney cancer follow up (14%).

III. Clinical Trials

Every kidney cancer patient in Canada 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 Canada 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.

Overall, the healthcare community in Canada has not been 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 had they been provided with the necessary information to make the decision. This, combined with the high rate of satisfaction of those who had participated in a trial, also indicates an obvious lost opportunity to improve the quality of care and survivorship of RCC patients through research.

Patients with rarer sub-types and those in various stages of their treatment pathway were not being approached equally to participate in clinical trials. It is notable that nearly half were approached after surgery rather than upon initial diagnosis.

Patients who HAD DISCUSSIONS about clinical trials

- According to survey results, clinical trials were not discussed with 40% of patients in Canada (33% globally).
- Of those who had discussions about clinical trials, those discussions occurred with:
 - Another patient (11%),
 - Doctors (83% compared to 75% globally),
 - Spouses, friends or family (17% compared to 31% globally),
 - Nurses (17%, a Global Outlier, compared to 10% globally),
 - Patient organisations (17%), and
 - Online groups (12%).

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

- 63% of patients in Canada had never been asked to participate in a clinical trial (70% globally).
- Of Canadian patients who had never been asked to participate in a clinical trial, 89% said it said it 'fairly likely'⁷ they would do so if asked.
- Of the patients in Canada who said they would be fairly likely⁸ to do so, they were being treated at:
 - Community/ local /general hospitals (34%),
 - Major cancer centres⁹ (45%),
 - Private clinics (3%), and
 - 7% at 'other'.
- Of the 89% of Canadian patients who said it would be 'fairly likely' they would participate in a clinical trial:
 - 44% said they would be 'likely' to participate (38% globally), and
 - 56% said they would require more information to make a decision of whether or not to do so (62% globally).

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

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

⁹ Including major cancer centres with kidney cancer specialists (36% compared to 30% globally).

- Of patients in Canada 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 (42%),
 - Major cancer centres¹⁰ (35% compared to 44% globally),
 - Private clinics (5%), and
 - Other (5%)

- Of those patients in Canada who would be 'fairly likely' to participate in a clinical trial if asked, this would be the case for:
 - 94% of patients with localised RCC (87% globally),
 - 100% of those with metastatic RCC (92% globally), and
 - 87% of those with no evidence of the disease or were told they were cured.

- 54% of patients in Canada with clear cell RCC (67% globally) and 74% of those with other sub-types 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 centres¹¹ (25% compared to 47% globally),
 - Private clinics (5%), and
 - Other (28%, a Global Outlier, compared to 9% globally).

Patients who HAD BEEN ASKED to participate in a clinical trial

- Of the patients in Canada who were asked to participate in a clinical trial:
 - 7% of their initial discussions had been with another patient,
 - 87% with doctors,
 - 14% with spouses, family or friends (31% globally),
 - 21% with nurses (15% globally),
 - 12% with patient organisations (18% globally),
 - 14% with online groups, and
 - 5% had no previous discussion with anyone.

¹⁰ Including major cancer centres with kidney cancer specialists (24% compared to 30% globally)

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

- The option of a clinical trial had first been discussed with:
 - 29% upon diagnosis (24% globally),
 - 49% of patients after surgery,
 - 13% after other treatments (21% globally), and
 - 9% who had been left with no other treatment options.

- For patients in Canada who had the option of a clinical trial first discussed with them after surgery:
 - 21% were being treated at community/local or general hospitals,
 - 79% at major cancer centres¹² (72% globally), and
 - 0% at private clinics.

- When the option of a clinical trial was discussed with patients:
 - 48% understood very well the risks and benefits of participating,
 - 41% had at least some understanding, and
 - 11% had a very limited understanding.

- Of those in Canada who had been asked to participate in a clinical trial, 79% agreed (86% globally).

- Those who had agreed to participate did so because:
 - Their doctor recommended it (73%, a Global Outlier, as compared to 55% globally),
 - They thought it might offer better care (65%),
 - They wanted a specific type of treatment (17% compared to 13% globally),
 - It was their only option for treatment (16% compared to 22% globally),
 - They wanted to help kidney cancer research (44% compared to 39% globally), and
 - Affordability, financial reasons (19% compared to 13% globally).

- 90% of patients in Canada who participated in a clinical trial were either 'very satisfied' or 'satisfied' with the experience, and of those:
 - 57% were 'very satisfied' (compared to 44% globally),
 - 33% were 'satisfied' (46% globally) and

¹² Including major cancer centres with kidney cancer specialists (69%).

- 10% were very dissatisfied.

- Those patients who had either never been asked to participate in a clinical trial or who had declined their participation provided the following reasons for their unwillingness to participate:
 - Lack of enough information to make a decision (10% compared to 19% globally),
 - Not eligible for the trial (21%),
 - Distrust of clinical trials (7% compared to 21% globally),
 - Fear of placebo (10% compared to 18% globally),
 - Fear of uncertainty (17% a Global Outlier, compared to 26% globally),
 - Extra tests or interventions required (21%),
 - Geographic distance (21% compared to 16% globally),
 - Affordability, financial costs (3%),
 - Not available at my hospital (10%),
 - Toxicity of treatment (14% a Global Outlier, compared to 22% globally), and
 - Other (31% a Global Outlier, compared to 16% globally).

IV. Quality of Care

Kidney cancer has a profound effect on the lives of patients in Canada as demonstrated by the impact of both physical and psychosocial issues, and the barriers standing in the way of receiving quality care.

There is strong evidence to suggest that RCC patients in Canada 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. Despite these results, compared to global results, Canadian patients were considerably more open with their doctors, this presenting an opportunity to explore best practices. 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 Canada to advocate for change and to provide support for patients who struggle with barriers to quality care. Unfortunately, younger patients, male patients and those with rarer sub-types are bearing the brunt of these barriers, preventing them from attaining a better quality of life.

Although RCC patients in Canada fared notably well compared to patients globally for physical conditions and psychological issues, fatigue, sleeplessness, disease related anxiety and the fear of recurrence were reported as the greatest factors affecting their well-being.

Although male and female RCC patients have a similar biological experience with kidney cancer, male patients in Canada were notably more impacted than female patients by a plethora of physical conditions and psychosocial issues. However, compared to global results, Canadian

patients were considerably less impacted by the physical and psychosocial issues.

Despite the fact that patients diagnosed since 2013 in Canada were notably more impacted by a number of physical conditions than for those diagnosed prior to that time, overall, these were considerably less impactful than for patients in other countries.

As expected, metastatic patients were notably more impacted by both physical conditions and psychosocial issues than those in other stages of the disease. However, it is surprising that patients with localised RCC were notably more impacted by specific physical conditions and psychosocial issues than metastatic patients were.

Compared to patients globally, Canadian patients experienced considerably more 'difficult times' waiting for surgery or scan results.

Despite the fact that 92% of Canadian RCC patients were impacted by psychosocial issues, and that a very high percentage found their doctors to be helpful when they did reach out, as many as half did not communicate their emotional issues to their healthcare team. However, compared to patients globally, Canadian patients were considerably more open with their doctors.

Although Canadian patients experienced notably fewer barriers to receiving quality care than patients globally, younger patients (30-45 yrs.), male patients and patients with rarer sub-types experienced notably more.

Treatment for Kidney Cancer

- According to survey results, 10% of Canadian 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 Canada were not receiving any treatments at all (a Global Outlier, compared to 7% globally).
- As shown in Table 4, for their first treatment,
 - 45% received them from community/local or general hospitals,
 - 39% at major cancer centres¹³,
 - 1% from private clinics (7% globally), and
 - 5% from other treatment centres.
- Of those patients in Canada who had been receiving treatments since that time:
 - 27% had been receiving them from community/local or general hospitals,
 - 52% from major cancer centres¹⁴,
 - 3% from private clinics, and
 - 8% at other treatment centres.
- As can be seen in Table 4, there was a notable migration of patients initially treated at community/local or general hospitals to major cancer centres, as evidenced by a decline of 18% in community/local or general hospitals , and an increase of 13% to major cancer centres.

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

PLACE OF TREATMENT	First Treatment	Subsequent Treatments	Notable Differences
Community/local/general hospitals	45%	27%	18%
Major cancer centres	39%	52%	13%
Private clinics	1%	3%	
Other	5%	8%	

¹³ Including major cancer centres with kidney cancer specialists (30%).

¹⁴ Including major cancer centres with kidney cancer specialists (44% compared to 36% globally)

Physical Conditions

- As can be seen in Table 5, 13% of Canadian patients had not been impacted by any physical conditions affecting their well-being since their initial diagnosis (a Global Outlier, compared to 8% globally).

- Of those impacted, fatigue was the condition affecting them the most, followed by:
 - Bowel changes, and
 - Sleeplessness.

- Patients in Canada were notably less impacted than patients globally by:
 - Mucositis/mouth ulcers,
 - Skin reactions and by
 - Nausea and vomiting.

- Patients in Canada were considerably less impacted by physical conditions overall than patients globally, and considerably less by:
 - Muscle weakness (26% a Global Outlier, compared to 32% globally), and by
 - Hair loss (7% a Global Outlier, compared to 13% globally).

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

PHYSICAL CONDITIONS	Global	Canada	Notable Differences
NOT AFFECTED	8%	13%	5%
Fatigue	66%	69%	
Trouble concentrating	24%	25%	
Mucositis/mouth ulcers	17%	12%	5%
Muscle weakness	32%	26%	6%
Pain related to surgery	29%	28%	
Bowel changes	33%	33%	
Loss of appetite	25%	23%	
Changes in taste and smell	25%	25%	
Sleeplessness	31%	30%	
Itching	17%	15%	
Hair loss	13%	7%	6%
Change of hair colour	17%	13%	
Memory loss	13%	14%	
Changes in sexual function	15%	14%	
Aching joints	22%	24%	
Sore feet and hands	23%	19%	
Weight loss	24%	22%	
Cramps	11%	14%	
Fluid retention	12%	14%	
Skin reactions	17%	11%	6%
Nausea and vomiting	22%	15%	7%
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- As can be seen in Table 6, female patients in Canada were notably more impacted by than males for trouble concentrating, pain related to surgery, hair loss and fluid retention compared to male patients.
- Canadian male patients were notably more impacted than females overall by physical conditions affecting their well-being, and by the physical conditions listed in the Table.

Table 6
Notable Differences in Canada for
Physical Conditions by Gender

PHYSICAL CONDITION	Males	Females	Notable Differences
NOT AFFECTED	7%	21%	14%
Fatigue	76%	59%	17%
Trouble concentrating	21%	30%	9%
Mucositis/mouth ulcers	17%	5%	12%
Muscle weakness	32%	17%	15%
Pain related to surgery	22%	37%	15%
Bowel changes	38%	26%	12%
Loss of appetite	29%	15%	14%
Changes in taste and smell	35%	11%	24%
Sleeplessness	36%	23%	13%
Itching	15%	16%	
Hair loss	5%	10%	5%
Change of hair colour	18%	7%	11%
Memory loss	15%	13%	
Changes in sexual function	21%	6%	15%
Aching joints	25%	23%	
Sore feet and hands	22%	14%	8%
Weight loss	25%	18%	7%
Cramps	17%	10%	7%
Fluid retention	10%	20%	10%
Skin reactions	14%	8%	6%
Nausea and vomiting	14%	17%	
LEGEND			
Most negative			
Most positive			

- Table 7 illustrates Global Outliers for physical conditions affecting patients' well-being in Canada by gender.
- For example, in Canada male patients were considerably worse off with cramps than male patients in other countries.

Table 7
Global Outliers for Canada
Physical Conditions by Gender

PHYSICAL CONDITION	Males	Females
NOT AFFECTED		21%
Cramps	17%	
Mucositis/mouth ulcers		5%
Muscle weakness		17%
Changes in taste and smell		11%
Sleeplessness		23%
Hair loss		10%
Change of hair colour		7%
Fluid retention		20%
LEGEND		
Negative Global Outlier for Canada		
Positive Global Outlier for Canada		

- As Table 8 shows, patients diagnosed in 2014 and later, overall, were notably more impacted by physical conditions affecting their well-being than patients diagnosed prior to 2014.

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

PHYSICAL CONDITION	Prior to 2014	2016 and Later	Notable Differences
NOT AFFECTED	19%	8%	11%
Fatigue	60%	75%	15%
Trouble concentrating	20%	28%	8%
Mucositis/mouth ulcers	11%	12%	
Muscle weakness	22%	28%	6%
Pain related to surgery	26%	30%	
Bowel changes	31%	35%	
Loss of appetite	15%	29%	14%
Changes in taste and smell	18%	30%	12%
Sleeplessness	23%	36%	13%
Itching	12%	18%	6%
Hair loss	6%	8%	
Change of hair colour	11%	15%	
Memory loss	13%	15%	
Changes in sexual function	15%	14%	
Aching joints	22%	25%	
Sore feet and hands	18%	19%	
Weight loss	15%	28%	13%
Cramps	14%	14%	
Fluid retention	16%	13%	
Skin reactions	10%	12%	
Nausea and vomiting	14%	16%	
LEGEND			
Most negative			
Most positive			

- Table 9 illustrates Global Outliers for physical conditions affecting patients' well-being in Canada by year of diagnosis.
- For example, Canadian patients diagnosed both prior to and later than 2014 were considerably less impacted by physical conditions overall than patients diagnosed during those times in other countries.
- Canadian patients diagnosed prior to 2014 were impacted by the least number of physical conditions per patient compared to patients diagnosed at that time in other countries.¹⁵

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

PHYSICAL CONDITION	Prior to 2014	2014 and Later
NOT AFFECTED	19%	8%
Muscle weakness	22%	
Changes in sexual function	15%	
Sore feet and hands	18%	
Hair loss		8%
LEGEND		
Negative Global Outlier for Canada		
Positive Global Outlier for Canada		

¹⁵ For further detail, see the IKCC Global Report

- Table 10 shows notable differences between patients in various stages of RCC by physical conditions in Canada.
- Metastatic patients were notably more impacted by bowel changes than those with localised RCC or who had no evidence of disease/ had been told they were cured.

Table 10
Notable Differences in Canada for
Physical Conditions by Stage

PHYSICAL CONDITION	Localised RCC	Metastatic RCC	No Evidence/ Cured
NOT AFFECTED	12%	2%	30%
Fatigue	68%	85%	46%
Trouble concentrating	20%	27%	21%
Mucositis/mouth ulcers	12%	20%	4%
Muscle weakness	24%	38%	13%
Pain related to surgery	20%	27%	33%
Bowel changes	16%	57%	15%
Loss of appetite	24%	36%	9%
Changes in taste and smell	24%	42%	9%
Sleeplessness	36%	36%	21%
Itching	12%	17%	13%
Hair loss	0%	10%	5%
Change of hair colour	0%	30%	1%
Memory loss	12%	16%	9%
Changes in sexual function	16%	18%	9%
Aching joints	16%	32%	15%
Sore feet and hands	16%	33%	8%
Weight loss	32%	34%	9%
Cramps	20%	18%	9%
Fluid retention	8%	16%	11%
Skin reactions	8%	19%	4%
Nausea and vomiting	16%	24%	8%
LEGEND			
Most negative			
Most positive			

- Table 11 illustrates Global Outliers for physical conditions affecting patients' well-being in Canada by stage.
- For example, Canadian patients with metastatic RCC were considerably less impacted by hair loss than patients in other countries.

Table 11
Global Outliers for Canada
Physical Conditions by Stage

PHYSICAL CONDITION	Localised RCC	Metastatic RCC	No Evidence/ cured
NOT AFFECTED			30%
Fatigue			46%
Change of hair colour	0%		
Hair loss	0%	10%	
LEGEND			
Negative Global Outlier for Canada			
Positive Global Outlier for Canada			

Psychosocial Issues¹⁶

- As can be seen in Table 12, 8% of Canadian patients had not had their sense of emotional well-being impacted by psychosocial issues since their initial diagnosis (a Global Outlier, compared to 4% globally).
- Of those impacted, disease related anxiety was the issue that affected them the most, followed by fear of recurrence.
- Compared to patients globally, patients in Canada were notably more impacted by general anxiety and difficulty navigating the healthcare system, and notably less impacted by stress related to financial issues.

¹⁶ <https://en.wikipedia.org/wiki/Psychosocial>

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

PSYCHOSOCIAL ISSUE	Global	Canada	Notable Differences
NOT AFFECTED	4%	8%	
General anxiety	31%	38%	7%
Disease-related anxiety	60%	56%	
Fear of dying	44%	43%	
Fear of recurrence	50%	53%	
Depression	27%	30%	
Isolation	16%	14%	
Changes in relationships	28%	27%	
Difficulty on the job or in school	19%	15%	
Stress related to financial issues	28%	18%	10%
Loss or reduction in employment	20%	22%	
Difficulty navigating the healthcare system	14%	19%	5%
Problems getting life or health insurance	13%	13%	
Concerns about body image/physical appearance	22%	19%	
Relationships with friends/others	18%	16%	
Sexuality	14%	12%	
LEGEND			
Negative			
Positive			

- According to Table 13, males in Canada were impacted notably more by psychosocial issues than females, disease-related anxiety affecting males the most.
- Females were affected notably more than males for the fear of recurrence, followed by psychological concern for changes in relationships.

Table 13
Notable Differences in Canada for
Psychosocial Issues by Gender

PSYCHOSOCIAL ISSUE	Males	Females	Notable Differences
NOT AFFECTED	8%	8%	
General anxiety	48%	25%	23%
Disease-related anxiety	64%	47%	17%
Fear of dying	47%	38%	9%
Fear of recurrence	44%	64%	20%
Depression	34%	25%	9%
Isolation	14%	13%	
Changes in relationships	25%	30%	5%
Difficulty on the job or in school	17%	13%	
Stress related to financial issues	18%	18%	
Loss or reduction in employment	22%	22%	
Difficulty navigating the healthcare system	17%	21%	
Problems getting life or health insurance	15%	12%	
Concerns about body image/physical appearance	19%	19%	
Relationships with friends/others	18%	13%	5%
Sexuality	15%	7%	8%
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- Table 14 illustrates Global Outliers for psychosocial issues affecting patient emotional well-being in Canada by gender.
- For example, overall, females were considerably less impacted by psychosocial issues compared to females in other countries.

Table 14
Global Outliers for Canada
Psychosocial Issues by Gender

PSYCHOSOCIAL ISSUE	Males	Females
NOT AFFECTED		8%
General anxiety	48%	
LEGEND		
Negative Global Outlier for Canada		
Positive Global Outlier for Canada		

- As shown in Table 15, patients diagnosed 2014 and later were more notably impacted than those diagnosed prior to 2014 by:
 - Stress related to financial issues,
 - Fear of dying,
 - Depression, and by
 - Difficulty navigating the healthcare system.
- Those diagnosed prior to 2014 were more notably impacted by difficulty on the job or in school.

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

PSYCHOSOCIAL ISSUE	Prior to 2014	2014 and Later	Notable Differences
NOT AFFECTED	10%	6%	
General anxiety	36%	39%	
Disease-related anxiety	57%	56%	
Fear of dying	37%	48%	11%
Fear of recurrence	53%	53%	
Depression	21%	37%	16%
Isolation	15%	13%	
Changes in relationships	26%	27%	
Difficulty on the job or in school	21%	11%	10%
Stress related to financial issues	15%	21%	6%
Loss/reduction in employment	24%	20%	
Difficulty navigating the health care system	12%	24%	12%
Problems getting life or health insurance	15%	12%	
Concerns about body image/physical appearance	21%	18%	
Relationships with friends/other	14%	17%	
Sexuality	14%	10%	
LEGEND			
Most negative			
Most positive			

- Table 16 shows Global Outliers for psychosocial issues affecting patients' emotional well-being in Canada by year of diagnosis.
- For example, Canadian patients diagnosed both before and after 2014 were considerably less affected by psychosocial issues than patients diagnosed at those times in other countries.

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

PSYCHOSOCIAL ISSUE	Prior to 2014	2014 and Later
NOT AFFECTED	10%	6%
General anxiety	36%	
Difficulty navigating the healthcare system		24%
Stress related to financial issues		21%
LEGEND		
Negative Global Outlier for Canada		
Positive Global Outlier for Canada		

- Table 17 details specific psychosocial issues affecting Canadian patients' well-being in their various stages of RCC.
- For example, patients who had no evidence of the disease or who had been told they were cured were more notably impacted by the fear of recurrence than patients with either metastatic or localised RCC.

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

PSYCHOSOCIAL ISSUE	Localised RCC	Metastatic RCC	No Evidence/ cured
NOT AFFECTED	24%	6%	6%
General anxiety	40%	41%	33%
Disease-related anxiety	44%	70%	45%
Fear of dying	40%	51%	37%
Fear of recurrence	48%	34%	73%
Depression	36%	32%	21%
Isolation	24%	14%	10%
Changes in relationships	28%	32%	21%
Difficulty on the job or in school	12%	22%	13%
Stress related to financial issues	20%	22%	17%
Loss or reduction in employment	20%	30%	12%
Difficulty navigating the healthcare system	20%	22%	16%
Problems getting life or health insurance	12%	16%	11%
Concerns about body image/physical appearance	20%	28%	12%
Relationships with friends/others	16%	20%	10%
Sexuality	4%	20%	6%
LEGEND			
Most negative			
Most positive			

- Table 18 illustrates Global Outliers for patients' psychosocial issues by stage.
- For example, patients with localised RCC were considerably more impacted by isolation than patients with localised RCC in other countries.

Table 18
Global Outliers for Canada
Psychosocial Issues by Stage

PSYCHOSOCIAL ISSUE	Localised RCC	Metastatic RCC	No Evidence/ cured
NOT AFFECTED	24%		
Disease-related anxiety	44%		
Isolation	24%		
Stress related to financial issues	20%		
Relationships with friends/other			10%
Negative Global Outlier for Canada			
Positive Global Outlier for Canada			

Patient Timeline- Most Difficult Times

- According to Table 19, Canadian patients experienced the most difficult times with kidney cancer during the process of diagnosis, and waiting for surgery or scan results.
- Compared to patients globally, patients in Canada were affected considerably more waiting for surgery or scan results (51%, a Global Outlier compared to 37% globally), and notably less than patients globally during their treatment for recurrence.

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

MOST DIFFICULT TIME	Global	Canada	Notable Differences
NOT AFFECTED	2%	2%	
During the process of diagnosis	51%	55%	
Surveillance period	19%	16%	
Surgery & recovery afterwards	38%	42%	
Follow up scans	17%	14%	
Waiting for surgery or scan results	37%	51%	14%
Diagnosis of recurrence	21%	19%	
Treatment for recurrence	10%	5%	5%
Diagnosis of further disease progression	23%	23%	
Dealing with side effects of treatment	29%	26%	
Transition to palliative care	4%	2%	
Long term adjustment, survivorship	12%	8%	
LEGEND			
Negative			
Positive			

- As shown in Table 20, females in Canada were affected notably more than males by:
 - Surgery and recovery afterwards,
 - Follow-up scans,
 - Waiting for surgery or scan results, and by
 - Diagnosis of recurrence.

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

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

MOST DIFFICULT TIME	Males	Females	Notable Differences
NOT AFFECTED	3%	1%	
During the process of diagnosis	56%	53%	
Surveillance period	15%	17%	
Surgery and recovery afterwards	37%	48%	11%
Follow up scans	12%	17%	5%
Waiting for surgery or scan results	42%	61%	19%
Diagnosis of recurrence	17%	22%	5%
Treatment for recurrence	5%	4%	
Diagnosis of further disease progression	27%	17%	10%
Dealing with side effects of treatment	37%	13%	24%
Transition to palliative care	2%	1%	
Long term adjustment, survivorship	9%	6%	
LEGEND			
Most negative			
Most positive			

- Table 21 illustrates Global Outliers for patients' most difficult times in Canada by gender.
- For example, both male and female Canadian patients were considerably worse off waiting for surgery or scan results than male and female patients in other countries.

Table 21
Global Outliers for Canada
Most Difficult Times by Gender

MOST DIFFICULT TIME	Males	Females
Waiting for surgery or scan results	42%	61%
Dealing with side effects of treatment		13%
LEGEND		
Negative Global Outlier for Canada		
Positive Global Outlier for Canada		

Communication and Support from Healthcare Professionals

- Of those patients in Canada who experienced psychosocial issues 51% said they communicated the issues to a healthcare professional, while 49% had not done so.
- In Canada:
 - 58% were very open and told the doctor everything in great detail (a Global Outlier, compared to 47% globally),
 - 26% shared some of their issues, but not to the full extent (compared to 31% globally),
 - 13% held back some details and minimized their symptoms and side effects or chose not to communicate their issues at all, and
 - 2% had not had the opportunity to communicate their issues at all.
- Of patients in Canada who chose to tell the doctor or everything in great detail about their psychosocial issues this was the case for:
 - 65% of male patients (a Global Outlier, compared to 52% globally, and 49% of female patients (42% globally),
 - 50% of those aged 30-45 yrs. (39% globally),
 - 59% of patients¹⁷ aged 46-65 yrs. (49% globally), and
 - 60% aged 66+ yrs. (54% globally)
- For those who communicated their issues 93% of patients found their doctors to be helpful, while this had not been the case for the remaining 7%.
- Of those, 58% found them to be very helpful (a Global Outlier, compared to 50% globally), and 35% found them to be somewhat helpful (compared to 42% globally).

Barriers to Receiving Quality Care

- Patients in Canada had the following types of healthcare coverage:
 - Government healthcare (93% compared to 73% globally),
 - Private insurance (32%, compared to 39% globally),
 - Self-coverage (9%, compared to 14% globally), and
 - Family coverage (2%).

¹⁷ Due to insufficient sample sizes, data was not reported for the under 30 yr. age brackets.

- As Table 22 shows, 51% of patients in Canada had not experienced any barriers to receiving quality care (compared to 39% globally).
- Wait time to treatment was the greatest barrier.
- Compared to patients globally, overall, patients in Canada were notably less impacted by barriers to treatment, and by the lack of affordability/cost of treatment.

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

BARRIER TO RECEIVING QUALITY CARE	Global	Canada	Notable Differences
NOT AFFECTED	39%	51%	12%
Lack of affordability, cost of treatment	21%	8%	13%
Lack of access to treatment centre (travel)	13%	9%	
Inability to understand the treatment	6%	2%	
Lack of access to up-to-date treatment/equipment	14%	12%	
Wait time to treatment was longer than necessary	18%	19%	
Lack of personal support	14%	11%	
No specialty doctor available locally	13%	12%	
Difficulty managing career/caregiver role while in treatment	9%	6%	
Fear of discrimination by my employer/ friends/ family	9%	6%	
No available treatments	5%	2%	
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- According to Table 23, younger patients (30-45 yrs.) in Canada were affected overall by notably more barriers than older age groups.
- Those 66+ yrs. experienced relatively fewer barriers.

Table 23
Notable Differences in Canada for
Barriers to Receiving Quality Care by Age¹⁸

BARRIER TO RECEIVING QUALITY CARE	30-45 yrs.	46-65 yrs.	66+ yrs.
NOT AFFECTED	11%	50%	63%
Lack of affordability, cost of treatment	11%	8%	6%
Lack of access to treatment centre (travel)	5%	11%	7%
Inability to understand the treatment	5%	0%	4%
Lack of access to up-to-date treatment/equipment	11%	16%	7%
Wait time to treatment was longer than necessary	16%	21%	17%
Lack of personal support	21%	12%	6%
No specialty doctor available locally	11%	13%	8%
Difficulty managing career/caregiver role while in treatment	26%	4%	5%
Fear of discrimination by my employer/ friends/ family	16%	7%	4%
No available treatments	5%	2%	1%
LEGEND			
Most negative			
Most positive			

- Table 24 shows notable differences in Canada for barriers to receiving quality care by gender.
- For example, males were notably more affected by lack of personal support while females were more notably affected by the lack of affordability/cost of treatment.

¹⁸ Due to insufficient sample size, data is not reported for the under 30 yr. age bracket.

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

BARRIER TO RECEIVING QUALITY CARE	Males	Females	Notable Differences
NOT AFFECTED	44%	56%	12%
Lack of affordability, cost of treatment	4%	10%	6%
Lack of access to treatment centre (travel)	11%	7%	
Inability to understand the treatment	1%	2%	
Lack of access to up-to-date treatment/equipment	12%	12%	
Wait time to treatment was longer than necessary	20%	18%	
Lack of personal support	15%	8%	7%
No specialty doctor available locally	13%	10%	
Difficulty managing career/caregiver role while in treatment	8%	5%	
Fear of discrimination by my employer/ friends/ family	8%	5%	
No available treatments	1%	2%	
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- As shown in Table 25, overall, patients with other sub-types experienced notably more barriers to treatment in receiving quality care than patients with clear cell RCC.
- Specifically, they were affected by:
 - Inability to understand the treatment,
 - Lack of access to the most up to date treatment, and by
 - No available treatments.
- Clear cell RCC patients experienced notably more barriers from lack of access to treatment centres, and for the lack of locally available specialty doctors.

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

BARRIER TO RECEIVING QUALITY CARE	Clear Cell	Other sub-types	Notable Differences
NOT AFFECTED	51%	44%	7%
Lack of affordability, cost of treatment	8%	6%	
Lack of access to treatment centre (travel)	11%	2%	9%
Inability to understand the treatment	1%	15%	14%
Lack of access to up-to-date treatment/equipment	13%	19%	6%
Wait time to treatment was longer than necessary	20%	13%	7%
Lack of personal support	11%	15%	
No specialty doctor available locally	11%	4%	7%
Difficulty managing career/caregiver role while in treatment	7%	8%	
Fear of discrimination by my employer/ friends/ family	4%	4%	
No available treatments	0%	6%	6%
LEGEND			
Most negative			■
Most positive			■

V. Opportunities to Improve Care

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

Surveillance

- At the time of the survey, patients in Canada were in the following stages of their RCC:
 - 8% were in Stage 1 or 2 (13% globally),
 - 3% in Stage 3 (8% globally),
 - 39% in Stage 4,
 - 28% had no evidence of the disease (19% globally), and
 - 9% had been told they were cured, and
 - 3% had died.

- Their last follow up scan had occurred:
 - Less than one year ago (86%),
 - 1-3 years ago (10%), and
 - More than 3 years ago (2%).

- Most recent follow up scans had occurred more than three years ago for:
 - 0% of those in Stage 1 or 2¹⁹,
 - 0% of those in Stage 4,
 - 4% of those who had no evidence of the disease or had been told they were cured,

 - 0% of those aged 30-45 yrs.²⁰,
 - 1% of those aged 46-65,
 - 5% of those aged 66+ yrs.,

 - 1% of males,
 - 4% of females,

 - 3% of those with no understanding of kidney cancer guidelines, and
 - 3% of those with no understanding of the guidelines for kidney cancer follow up.

¹⁹ Due to insufficient data, results are not reported for Stage 3 or for patients who have died

²⁰ Due to insufficient data, results are not reported for under 30 yr. age brackets

VI. Shared decision making

As shared decision making becomes increasingly recognized as a pillar of patient-centered healthcare, IKCC and its Affiliate Organisations have the opportunity to play a key role in Canada 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 Canada followed 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 those being treated at major cancer centres, for the very young and the very old, and for those in Stage 4 of their disease, had no evidence of RCC, or who had been told they were cured.

There is a possibility that shared decision making in Canada has improved notably for patients diagnosed since 2016.

- 25% of patients in Canada had not been engaged at all in their treatment plans, in that their doctor had decided their treatment plan solely for them.
- Of those patients who were involved in their treatment decision:
 - 8% 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 Canadian patients with their treatment plans:
 - Partner/spouse (63% compared to 56% globally),
 - Parents (7%, compared to 13% globally),
 - Children (17%),
 - Friends/other family members (14% compared to 20% globally),
 - Local family doctor (28% compared to 22% globally), and
 - A patient organisation (10%).
- 20% of patients made the decision by themselves, and for 4%, the decision had rested on their personal financial situation.

- Of those patients in Canada where treatment plans had been decided for them solely by their doctors without any input from the patient:
 - 33% were being treated in community centres/local or general hospitals,
 - 45% at major cancer centres²¹, and
 - 2% at private clinics (9% globally).

- In the case where treatment plans were decided solely by the doctor without any input from the patient, this affected:²²
 - 29% of those aged 30-45 yrs.,
 - 19% of those aged 46-65 yrs. (a Global Outlier, compared to 30% globally),
 - 34% of those aged 66+ yrs. (27% globally),

 - 16% of those in Stage 1 or 2²³ (25% globally),
 - 27% of those in Stage 4,
 - 26% of those who had no evidence of the disease or who were told they were cured (31% globally),

 - 25% of males,
 - 25% of females (30% globally),

 - 28% of those diagnosed prior to 2016, and
 - 21% of those diagnosed 2016 and later (compared to 30% globally).

²¹ Including major cancer centres with kidney cancer specialists (37%, a Global Outlier compared to 30% globally),

²² Due to insufficient sample size, data is not reported for the under 30 age brackets.

²³ Due to insufficient sample sizes, data is not available for patients in Stage 3 or who had died.

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

APPENDIX

Methodology

Data Collection

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

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

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

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

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

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

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

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

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

Derived Questions

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

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

Outliers

Outliers were used in two ways in the analysis:

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

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

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

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