



2018 IKCC PATIENT SURVEY

-Germany-

Prepared for:
International Kidney Cancer Coalition
January 2019

TABLE OF CONTENTS

INTRODUCTION	4
KEY FINDINGS- Germany	6
SURVEY RESULTS- Germany	8
I. Respondent Profile	8
II. Knowledge and Understanding	9
Year of Diagnosis.....	10
Success of Timely Diagnosis.....	10
Patient Knowledge and Understanding.....	12
III. Clinical Trials	15
Patients who had NEVER BEEN ASKED to participate in a clinical trial.....	16
Patients who HAD BEEN ASKED to participate in a clinical trial.....	18
IV. Quality of Care	20
Physical Conditions.....	23
Psychosocial Issues.....	29
Patient Timeline- Most Difficult Times.....	35
Communication and Support from Healthcare Professionals.....	37
Barriers to Receiving Quality Care.....	38
V. Opportunities to Improve Care	45
Surveillance.....	45
VI. Shared decision making	46
Acknowledgements	48
APPENDIX	49
Methodology	49
Data Collection.....	49
Derived Questions.....	50
Outliers.....	50
List of Tables	51

Preface

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

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

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

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

¹ <https://www.perceptioninsight.ca>

Reader's Notes

There are three types of tables in this report:

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

1. Global Outlier Tables

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

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

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 Germany, 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- Germany

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 all demographics;
- 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 for any future treatment decisions;
- Explore best practices in other countries related to healthcare communication with patients upon diagnosis that would help enhance patient knowledge and understanding about their disease, treatments and guidelines in Germany, 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 potential research subjects 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 their decision of whether or not to participate, particularly upon initial diagnosis.
- Contribute to the improvement in the quality of life for RCC patients by encouraging them to share their experiences about how kidney cancer has impacted their lives with their doctors, and by providing patients with the resources and tools to attain the psychological support they need;

- Advocate for change and provide support to patients who struggle with physical conditions, psychosocial issues and barriers standing in their way to receiving quality care, potentially citing Germany as an example of best practices to other countries;
- Bring specific attention and focus to patient sub groups that may for whatever reason go unnoticed by the healthcare community, as well as their particular struggles so that they too might benefit from a better patient experience and overall quality of life;
- Improve the survivorship of patients by empowering patients through education to advocate for regular surveillance despite gender, age or stage; and
- Advocate for shared decision making for patient treatment plans through further development of decision aid tools particularly for patient sub groups where there is evidence of notable physician directed care.

SURVEY RESULTS- Germany

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:

- Germany had 128 respondents, or 7% of the global total.
- 83% of those responding to the survey were kidney cancer patients (71% globally) while the remaining 17% defined themselves as a caregiver, family member or friend of the patient (29% globally).
- 57% of respondents were males, 41% were females, and 2% did not self-identify.
- Survey respondents had the following age profile:
 - Under 18 (0%),
 - 18-29 (0%),
 - 30-45 (9%, compared to 20% globally),
 - 46-65 (63% compared to 57% globally), and
 - 66+ (28% compared to 20% globally).
- Survey respondents were in the following stages of kidney cancer:
 - Localised kidney cancer (6% compared to 23% globally),
 - Metastatic (46%), and
 - No evidence/told they were cured (48% a Global Outlier, compared to 33% globally).

II. Knowledge and Understanding

IKCC and its Affiliate Organisations have an opportunity to play an instrumental role in advocating for the early and universal diagnosis of all RCC patients.

It is imperative that patients in Germany 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 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 so that they can best participate in determining any specific management strategies required for their particular sub-type that will ensure the most favourable outcome.

There is also an opportunity in Germany to enhance the means by which patients are educated about their disease in general upon diagnosis, and about any potential treatment and guidelines available to them throughout their patient experience. The fundamental communication challenge that doctors face in communicating this critical information to their patients upon initial diagnosis must be addressed.

Although compared to patients in other countries considerably more RCC patients in Germany were told their sub-type upon initial diagnosis, they reported the worst understanding of this foundational piece of information, of which all RCC patients should be aware. In fact, compared to patients in other countries, German patients had the lowest understanding per patient of their disease upon initial diagnosis and of patient treatment and guidelines.

Patients with clear cell in Germany had a notably poorer understanding of certain aspects of their disease compared to patients with rarer sub-types.

Compared to middle aged patients, older patients (66+ yrs.) in Germany took the longest to be correctly diagnosed with RCC.

Year of Diagnosis

- German patients who responded to this survey had been diagnosed in the following years:
 - 9% prior to 2005,
 - 2% in 2005,
 - 3% in 2006,
 - 4% in 2007,
 - 6% in 2008,
 - 6% in 2009,
 - 3% in 2010,
 - 9% in 2011,
 - 15% in 2012 (a Global Outlier, compared to 6% globally),
 - 6% in 2013,
 - 5% in 2014,
 - 9% in 2015,
 - 10% in 2016,
 - 6% in 2017 (a Global Outlier, compared to 20% globally), and
 - 9% in 2018.

Success of Timely Diagnosis

- Patients in Germany were in the following stages of their kidney cancer when they were first diagnosed:
 - 60% in Stages 1 or 2 (53% globally),
 - 24% in Stage 3, and
 - 14% in Stage 4 (a Global Outlier, compared to 26% globally).
- Following their first visit to the doctor, 66% of German patients were correctly diagnosed in less than a month (52% globally), while
 - 20% were diagnosed in 1-3 months (26% globally),
 - 8% in 3-6 months,
 - 3% in 6 months to a year, and
 - 3% in more than one year.
- 37% of patients in Germany were diagnosed at a family doctor or GP's office (20% globally),
 - 9% at an emergency department,
 - 24% at a community, local or general hospital (37% globally),

- 3% at a major cancer centre⁴ (13% globally),
 - 0% at a private clinic (11% globally) and
 - 27% at some other facility (a Global Outlier, compared to 7% globally).
- According to Table 1, there was no notable difference in the diagnosis of male versus female patients in Germany, with 85% of males and 88% of diagnosed in three months or less (compared to 82% of males and 73% of females globally).

Table 1
Notable Differences for
Time of Diagnosis by Gender

TIME OF DIAGNOSIS	Male	Female	Notable Differences
Less than month	68%	65%	
1-3 months	17%	23%	6%
3-6 months	10%	6%	6%
6 months-1 year	0%	6%	6%
More than 1 year	4%	0%	
LEGEND			
Most negative			
Most positive			

- As shown in Table 2, in Germany, older patients (66+ yrs.) took notably longer to be diagnosed, with 51% in less than a month compared to 76% of those aged 46-65 yrs.
- However, for a diagnosis in less than three months, there was no notable difference between the two age groups.

⁴ Including major cancer centres with kidney cancer specialists (2%, a Global Outlier compared to 8% globally)

Table 2
Notable Differences for
Time of Diagnosis by Age⁵

TIME OF DIAGNOSIS	46-65 yrs.	66+ yrs.	Notable Differences
Less than month	76%	51%	25%
1-3 months	12%	34%	22%
3-6 months	8%	9%	
6 months-1 year	1%	3%	
More than 1 year	3%	3%	
LEGEND			
Most negative			
Most positive			

Patient Knowledge and Understanding

- After their initial diagnosis 24% of patients in Germany were not told their sub-type (a Global Outlier, compared to 38% globally), and
 - 68% had no understanding of their stage (20% globally),
 - 86% had no understanding of their sub-type⁶ (43% globally),
 - 62% had no understanding of their treatment options (21% globally),
 - 64% had no understanding of their treatment recommendations (19% globally),
 - 68% had no understanding of the risk of recurrence (28% globally), and
 - 63% had no understanding of their likelihood of survival (25% globally),
 (All of these results being Global Outliers.)

- Patients in Germany had the lowest understanding per patient of their disease upon initial diagnosis compared to patients in other countries⁷.

⁵ Due to insufficient sample size, data is not available for the under 46 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.

⁷ For further detail see the IKCC Global Report

- As shown in Table 3, at the time of diagnosis:
 - Compared to patients with other sub-types, notably more patients in Germany with clear cell had less understanding about their stage, treatment recommendations and risk of recurrence; and
 - Both clear cell patients and those with other sub-types had the greatest lack of understanding for sub-type (88% of those with clear cell and 86% 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	72%	66%	6%
Sub-type	88%	86%	
Treatment options	63%	59%	
Treatment recommendations	65%	56%	9%
Risk of recurrence	69%	61%	8%
Likelihood of survival	62%	65%	
LEGEND			
Most negative			
Most positive			

- At the time of the survey, 7% of patients in Germany were still not aware of their sub-type.
- The 93% who were aware reported the following RCC sub-types:
 - Clear cell (66%),
 - Papillary (9%),
 - Chromophobe (6%),
 - Unclassified (6%),
 - XP11 Translocation Type (1%),
 - VHL (0%),
 - Renal Medullary (0%),
 - Collecting Duct (0%),
 - Transitional Cell Carcinoma (1%),
 - Renal Sarcoma (1%),

- Wilms Tumour (0%),
 - Benign Tumour (1%),
 - Other (3%).
-
- At the time of the survey, patients in Germany also had no understanding of the following:
 - Biopsies for kidney cancer (50% a Global Outlier, compared to 20% globally),
 - Surgical options (20% compared to 8% globally).
 - Immunotherapy (33% compared to 26% globally),
 - Targeted therapies (24%),
 - Radiation therapies (44% a Global Outlier, compared to 29% globally),
 - Ablative therapies (68% compared to 41% globally),
 - Palliative care (55% a Global Outlier, compared to 33% globally),
 - Active surveillance (48% a Global Outlier, compared to 29% globally),
 - Nutrition/lifestyle (15%),
 - Complementary therapies (36%),
 - Guidelines for kidney cancer care (25% a Global Outlier, compared to 20% globally), or for
 - Guidelines for kidney cancer follow up (16%).

 - Patients in Germany had the worst understanding overall about patient treatment and guidelines per patient than patients globally.⁸

⁸ Further details are available in the IKCC Global Report

III. Clinical Trials

Every kidney cancer patient deserves access to the highest quality care and the opportunity to participate in research. There is a lost opportunity in Germany to increase the quality of care of patients as well as the advancement of kidney cancer research as evidenced by the high degree of willingness amongst patients to participate should they be asked, and their high level of interest in moving this research forward through clinical trials.

There is high potential to tap into this resource of potential research subjects by providing them with the appropriate information particularly before surgery that will both motivate and make them feel comfortable in advocating for their own treatment decisions.

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

Overall, the healthcare community in Germany has not been proactive in approaching RCC patients about their possible participation in clinical trials.

The fact that 87% of patients who had never been approached to participate reported they would be amenable, particularly if provided with the necessary information to make the decision, and their willingness to help kidney cancer research points to a lost opportunity to improve the quality of care and survivorship of German RCC patients.

Compared to patients globally, German patients had the greatest number of reasons per patient as to why they were not willing to participate in a clinical trial. German patients reported considerably more of a lack of understanding and distrust of clinical trials than their global counterparts. This presents IKCC with the opportunity to provide patients with the

appropriate information addressing specific patient concerns so they can make an informed decision about participating.

Patients in various stages of their treatment pathway were not being approached equally to participate in clinical trials, given that the majority were asked following surgery rather than upon initial diagnosis.

Patients who HAD DISCUSSIONS about clinical trials

- According to survey results, clinical trials were not discussed with 45% of patients in Germany (33% globally).
- Of those who had discussions about clinical trials, those discussions occurred with:
 - Another patient (8%),
 - Doctors (61% compared to 75% globally),
 - Spouses, friends or family (11% compared to 31% globally),
 - Nurses (3%, compared to 10% globally),
 - Patient organisations (36% a Global Outlier, compared to 19% globally), and
 - Online groups (8% compared to 15% globally).

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

- 83% of patients in Germany had never been asked to participate in a clinical trial (compared to 70% globally).
- Of German patients who had never been asked to participate in a clinical trial, 87% said it said it 'fairly likely'⁹ they would do so if asked.
- Of the patients in Germany who said they would be fairly likely¹⁰ to do so, they were being treated at:
 - Community/ local /general hospitals (30% compared to 37% globally),
 - Major cancer centres¹¹ (27% compared to 45% globally),
 - 0% at private clinics (compared to 6% globally), and
 - 36% at 'other' (a Global Outlier, compared to 5% globally).

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 (17% compared to 30% globally),

- Of the 87% of Germans who said it would be 'fairly likely' they would participate in a clinical trial:
 - 42% said they would be 'likely' to participate, while
 - 58% would require more information to make a decision of whether or not to do so.

- Of patients in Germany who said they would need more information before they agreed to participate in a clinical trial, these patients were being treated¹² at:
 - Community/ local /general hospitals (17%),
 - Major cancer centres¹³ (28%), and
 - Private clinics (0%), and
 - 47% at 'other'.

- Patients who would be 'fairly likely' to participate in a clinical trial if asked consisted of:
 - 91% of those with metastatic RCC¹⁴, and
 - 88% of those with no evidence of the disease, or had been told they were cured.

- 80% of patients in Germany with clear cell RCC (a Global Outlier compared to 67% globally) and 91% 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 (7%, a Global Outlier, compared to 28% globally),
 - Major cancer centres¹⁵ (42% compared to 47% globally),
 - Private clinics (0% compared to 9% globally), and
 - 34% at 'other' (a Global Outlier compared to 9% globally).

¹² Due to insufficient sample size, data is reported for Germany but cannot be compared to global results (n=47)

¹³ Including major cancer centres with kidney cancer specialists (17%)

¹⁴ Due to insufficient sample size, data is not reported for patients with localised RCC

¹⁵ Including 28% for major cancer centres with kidney cancer specialists.

Patients who HAD BEEN ASKED to participate in a clinical trial

- Of the patients in Germany who were asked to participate in a clinical trial:
 - 10% of their initial discussions were with another patient,
 - 75% with doctors (88% globally),
 - 10% with spouses, family or friends (31% globally),
 - 0% with nurses (15% globally),
 - 10% with patient organisations (18% globally),
 - 10% with online groups (16% globally),
 - 15% with 'other' (a Global Outlier, compared to 1% globally), and
 - 0% had no previous discussion with anyone.

- The option of a clinical trial was first discussed with:
 - 21% upon diagnosis,
 - 63% of patients after surgery (a Global Outlier, compared to 49% globally),
 - 16% after other treatments (21% globally), and
 - 0% who were left with no other treatment options (6% globally).

- For patients in Germany who had the option of a clinical trial first discussed with them after surgery:
 - 36% were being treated at community/local or general hospitals (a Global Outlier, compared to 18% globally),
 - 36% at major cancer centres¹⁶ (72% globally),
 - 0% at private clinics, and
 - 27% at 'other' (a Global Outlier, compared to 1% globally).

- When the option of a clinical trial was discussed with patients:
 - 21% had understood very well the risks and benefits of participating (47% globally),
 - 37% had at least some understanding, and
 - 42% had a very limited understanding (a Global Outlier, compared to 12% globally).

- Of those in Germany who were asked to participate in a clinical trial, 74% agreed (a Global Outlier, compared to 86% globally).

¹⁶ Including 27% for major cancer centres with kidney cancer specialists a Global Outlier compared to 57% globally

- Those who agreed to participate did so because:
 - Their doctor recommended it (38% as compared to 55% globally),
 - They thought it might offer better care (15% a Global Outlier, compared to 61% globally),
 - They wanted a specific type of treatment (23% compared to 13% globally),
 - It was their only option for treatment (15% compared to 22% globally),
 - They wanted to help kidney cancer research (62% compared to 39% globally), and
 - Affordability, financial reasons (0% compared to 13% 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 (31% compared to 19% globally),
 - Not eligible for the trial (13% compared to 21% globally),
 - Distrust of clinical trials (44% a Global Outlier, compared to 21% globally),
 - Fear of placebo (25% compared to 18% globally),
 - Fear of uncertainty (31% compared to 26% globally),
 - Extra tests or interventions required (31% compared to 18% globally),
 - Geographic distance (44% a Global Outlier, compared to 16% globally),
 - Affordability, financial costs (0% compared to 7% globally),
 - Not available at my hospital (25% a Global Outlier, compared to 14% globally),
 - Toxicity of treatment (25%), and
 - Other (6% compared to 16% globally).

- Compared to patients globally, Germany had the greatest number of reasons per patient for which they were not willing to participate in a clinical trial.¹⁷

¹⁷ Further details are available in the IKCC Global Report

IV. Quality of Care

Kidney cancer has a profound effect on the lives of patients in Germany as demonstrated by their impacts from both physical conditions and psychosocial issues. However, the relative lack of impact compared to patients in other countries suggests there may be potential in exploring best practices.

There is strong evidence to suggest that RCC patients in Germany are choosing to 'suffer in silence' from the effects of their disease, not reaching out to their healthcare teams for the support they need to improve the quality of their lives. This constitutes a clear call to both IKCC and the healthcare community to encourage conversations with patients about how kidney cancer has affected their lives. Particular attention must be paid to more heavily impacted patient sub groups such as females, and those with no evidence of the disease, or who had been told they were cured, who often go unnoticed by the healthcare community.

Compared to patients globally, German patients were affected less overall by barriers to receiving quality care, this presenting an opportunity to explore best practices. There is also an opportunity for IKCC and its Affiliate Organisations to play a role in Germany to advocate for change and to provide support for patients who do in fact struggle with barriers standing in the way to their right of receiving quality care.

Although German patients were impacted by a number of physical conditions and psychosocial issues, overall they were considerably less affected than RCC patients in other countries.

Despite the fact that there are no biological differences in how male and female patients experience RCC, there were notable differences in how males and females in Germany were impacted by both physical conditions and psychosocial impacts. Overall, females were more notably affected than males for psychosocial issues affecting their well-being as well as for 'most difficult times'. Compared to patients globally, male patients in

Germany were impacted by the least number of psychosocial issues per patient, this presenting an opportunity to explore best practices.

Not surprisingly, metastatic patients in Germany were notably more impacted from physical conditions and psychosocial issues than patients who had no evidence of the disease, or who had been told they were cured. Even though German patients with no evidence of the disease, or who had been told they were cured, were impacted by the least number of psychosocial issues per patient compared to global results, they were impacted notably more than metastatic patients with disease related anxieties.

Despite the fact that 85% of patients in Germany were impacted by psychosocial issues, and a high percentage were finding their doctors to be helpful when they did reach out, as many as 46% were not communicating their emotional issues to their healthcare team.

Compared to patients in other countries, RCC patients in Germany experienced notably fewer barriers to receiving quality care overall. Older patients (66+ yrs.) and females were more affected overall.

Treatment for Kidney Cancer

- According to survey results, 2% of German patients had not had any treatment for their kidney cancer after their first diagnosis.
- At the time of the survey, 8% of patients in Germany were not receiving any treatments at all.
- As shown in Table 4, for their first treatment,
 - 69% received them from community/local or general hospitals (47% globally),
 - 24% at major cancer centres¹⁸ (38% globally),
 - 0% from private clinics (7% globally) and
 - 5% at 'other'.
- Of those patients in Germany who had been receiving treatments since that time:
 - 32% had been receiving them from community/local or general hospitals,
 - 27% from major cancer centres¹⁹ (51% globally),
 - 0% from private clinics (7% globally), and
 - 33% at 'other'.
- As can be seen in Table 4, there was a notable migration of patients initially treated at community/local or general hospitals to 'other' places of treatment, as evidenced by a decline of 37% in community/local or general hospitals , and an increase of 17% at 'other' places of treatment.

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

PLACE OF TREATMENT	First Treatment	Subsequent Treatments	Notable Differences
Community/local/general hospitals	69%	32%	-37%
Major cancer centres	24%	27%	
Private clinics	0%	0%	
Other	5%	33%	28%

¹⁸ Including 15% for major cancer centres with kidney cancer specialists, a Global Outlier compared to 26% globally.

¹⁹ Including 18% for major cancer centres with kidney cancer specialists (36% globally)

Physical Conditions

- As can be seen in Table 5, 14% of German patients were not impacted by any conditions affecting their physical well-being since their initial diagnosis (a Global Outlier, compared to 8% globally).

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

- Patients in Germany were more notably impacted than patients globally by fluid retention.

- They were considerably less impacted than patients globally by pain related to surgery, and notably less by:
 - Loss of appetite,
 - Memory loss,
 - Aching joints, and by
 - Nausea and vomiting.

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

PHYSICAL CONDITION	Global	Germany	Notable
NOT AFFECTED	8%	14%	6%
Fatigue	66%	68%	
Trouble concentrating	24%	30%	6%
Mucositis/mouth ulcers	17%	21%	
Muscle weakness	32%	30%	
Pain related to surgery	29%	22%	7%
Bowel changes	33%	39%	6%
Loss of appetite	25%	20%	5%
Changes in taste and smell	25%	25%	
Sleeplessness	31%	33%	
Itching	17%	16%	
Hair loss	13%	12%	
Change of hair colour	17%	19%	
Memory loss	13%	8%	5%
Changes in sexual function	15%	24%	9%
Aching joints	22%	15%	7%
Sore feet and hands	23%	20%	
Weight loss	24%	26%	
Cramps	11%	11%	
Fluid retention	12%	17%	5%
Skin reactions	18%	17%	
Nausea and vomiting	22%	17%	5%
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- As can be seen in Table 6, male patients in Germany were more notably affected than female patients by:
 - Mucositis/mouth ulcers,
 - Muscle weakness,
 - Changes in taste and smell,

- Changes in sexual function,
 - Weight loss,
 - Fluid retention, and by
 - Skin reactions.
- Females were more notably impacted than males by:
 - Fatigue,
 - Trouble concentrating,
 - Pain related to surgery,
 - Hair loss, and by
 - Cramps.

Table 6
Notable Differences in Germany for
Physical Conditions by Gender

PHYSICAL CONDITION	Males	Females	Notable Differences
NOT AFFECTED	14%	13%	
Fatigue	59%	79%	20%
Trouble concentrating	20%	44%	24%
Mucositis/mouth ulcers	27%	15%	12%
Muscle weakness	33%	27%	6%
Pain related to surgery	16%	31%	15%
Bowel changes	41%	38%	
Loss of appetite	22%	19%	
Changes in taste and smell	31%	17%	14%
Sleeplessness	30%	40%	10%
Itching	16%	17%	
Hair loss	8%	19%	11%
Change of hair colour	20%	19%	
Memory loss	8%	8%	
Changes in sexual function	31%	15%	16%
Aching joints	17%	13%	
Sore feet and hands	22%	19%	
Weight loss	30%	23%	7%
Cramps	9%	15%	6%
Fluid retention	20%	13%	7%
Skin reactions	22%	10%	12%
Nausea and vomiting	17%	17%	
LEGEND			
Most negative			
Most positive			

- Table 7 illustrates Global Outliers for physical conditions affecting patients' well-being in Germany by gender.
- For example, female patients were considerably worse off for trouble concentrating than female patients in other countries.

Table 7
Global Outliers for Germany
Physical Conditions by Gender

PHYSICAL CONDITION	Males	Females
NOT AFFECTED	14%	
Trouble concentrating		44%
Fluid retention	20%	
Pain related to surgery	16%	
LEGEND		
Negative Global Outlier for Germany		
Positive Global Outlier for Germany		

- As Table 8 shows, German patients diagnosed prior to 2014 were impacted considerably less than patients globally diagnosed at that time by physical conditions overall as well as for pain related to surgery.
- German patients were more notably affected than patients globally who were diagnosed prior to 2014 by mucositis/mouth ulcers, weight loss and by fluid retention.

Table 8
Notable Differences between Germany and Global Results
Physical Conditions for Patients Diagnosed Prior to 2014²⁰

PHYSICAL CONDITION	Global	Prior to 2014	Notable Differences
NOT AFFECTED	10%	15%	5%
Fatigue	65%	68%	
Trouble concentrating	24%	25%	
Mucositis/mouth ulcers	18%	24%	6%
Muscle weakness	29%	26%	
Pain related to surgery	26%	19%	7%
Bowel changes	38%	38%	
Loss of appetite	25%	21%	
Changes in taste and smell	27%	29%	
Sleeplessness	29%	33%	
Itching	17%	15%	
Hair loss	15%	14%	
Change of hair colour	19%	22%	
Memory loss	14%	8%	6%
Changes in sexual function	21%	21%	
Aching joints	23%	15%	8%
Sore feet and hands	25%	25%	
Weight loss	24%	29%	5%
Cramps	15%	13%	
Fluid retention	15%	21%	6%
Skin reactions	19%	14%	5%
Nausea and vomiting	25%	18%	7%
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- Table 9 illustrates notable differences in physical conditions between metastatic RCC patients, and patients with no evidence of the disease, or who had been told they were cured.
- Patients in Germany in the metastatic stage were more notably affected by virtually every physical condition listed than those with no evidence of the disease, or who had been told they were cured, with the exception of pain related to surgery.

²⁰ Due to insufficient data, results are not reported for patients diagnosed 2014 and later

Table 9
Notable Differences in Germany for
Physical Conditions by Stage²¹

PHYSICAL CONDITION	Metastatic RCC	No Evidence/ Cured	Notable Differences
NOT AFFECTED	5%	27%	20%
Fatigue	90%	53%	37%
Trouble concentrating	38%	29%	9%
Mucositis/mouth ulcers	33%	0%	33%
Muscle weakness	43%	12%	31%
Pain related to surgery	12%	29%	17%
Bowel changes	57%	20%	37%
Loss of appetite	29%	6%	23%
Changes in taste and smell	36%	6%	30%
Sleeplessness	43%	27%	16%
Itching	19%	8%	11%
Hair loss	24%	4%	20%
Change of hair colour	38%	2%	36%
Memory loss	17%	2%	15%
Changes in sexual function	33%	16%	17%
Aching joints	17%	12%	5%
Sore feet and hands	31%	2%	29%
Weight loss	43%	4%	39%
Cramps	21%	4%	17%
Fluid retention	17%	6%	11%
Skin reactions	17%	6%	11%
Nausea and vomiting	26%	0%	26%
LEGEND			
Most negative			
Most positive			

- Table 10 illustrates Global Outliers for physical conditions affecting patients' well-being in Germany by stage.
- For example, patients with metastatic RCC were considerably better off for pain related to surgery than metastatic patients in other countries.

²¹ Due to insufficient sample size, data is not reported for patients with localised RCC

Table 10
Global Outliers for Germany
Conditions Affecting Physical Well-being by Stage²²

PHYSICAL CONDITION	Metastatic RCC	No Evidence/ cured
NOT AFFECTED	5%	27%
Mucositis/mouth ulcers	33%	0%
Pain related to surgery	12%	
Trouble concentrating		29%
Muscle weakness		12%
Changes in sexual function		16%
Sore feet and hands		2%
Weight loss	43%	4%
Nausea and vomiting		0%
LEGEND		
Negative Global Outlier for Germany		
Positive Global Outlier for Germany		

Psychosocial Issues

- As can be seen in Table 11, 9% of German 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, the fear of recurrence affected them the most followed by disease-related anxiety and the fear of dying.
- Patients in Germany were more notably affected than patients globally by issues with sexuality.
- Overall they were considerably less impacted overall than patients globally and specifically by:
 - General anxiety,
 - Disease related anxiety,
 - Fear of dying, and by
 - Isolation.

²² Due to insufficient data, results are not reported for localised RCC patients

- They were notably less impacted by depression, stress related to financial issues, and by problems getting life/health insurance.

Table 11
Notable Differences between Germany and Global Results for Psychosocial Issues

PSYCHOSOCIAL ISSUE	Global	Germany	Notable Differences
NOT AFFECTED	4%	9%	5%
General anxiety	31%	15%	16%
Disease-related anxiety	60%	44%	16%
Fear of dying	44%	38%	6%
Fear of recurrence	50%	51%	
Depression	27%	19%	8%
Isolation	16%	8%	8%
Changes in relationships	28%	24%	
Difficulty on the job or in school	19%	17%	
Stress related to financial issues	28%	11%	17%
Loss or reduction in employment	20%	21%	
Difficulty navigating the healthcare system	14%	12%	
Problems getting life or health insurance	13%	8%	5%
Concerns about body image/physical appearance	22%	20%	
Relationships with friends/others	18%	18%	
Sexuality	14%	22%	8%
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- Female patients in Germany were more notably impacted overall than male patients by psychosocial issues and by a number of specific issues detailed in Table 12.

- Males were more notably affected than females by:
 - Disease related anxiety,
 - Changes in relationships,
 - Difficulty navigating the healthcare system,
 - Concerns about body image, and by
 - Sexuality.

Table 12
Notable Differences in Germany for
Psychosocial Issues by Gender

PSYCHOSOCIAL ISSUE	Males	Females	Notable Differences
NOT AFFECTED	12%	4%	8%
General anxiety	12%	17%	5%
Disease-related anxiety	48%	35%	3%
Fear of dying	36%	40%	
Fear of recurrence	42%	63%	21%
Depression	12%	29%	17%
Isolation	6%	10%	
Changes in relationships	27%	21%	6%
Difficulty on the job or in school	12%	23%	11%
Stress related to financial issues	7%	15%	8%
Loss or reduction in employment	18%	27%	9%
Difficulty navigating the healthcare system	15%	6%	9%
Problems getting life or health insurance	7%	8%	
Concerns about body image/physical appearance	22%	17%	5%
Relationships with friends/others	16%	21%	5%
Sexuality	25%	19%	6%
LEGEND			
Most negative			
Most positive			

- Table 13 illustrates Global Outliers for psychosocial issues affecting patients' emotional well-being in Germany by gender.
- For example, both males and females were considerably better off for general anxiety than male and female patients in other countries.

- Male patients in Germany were impacted by the least number of psychosocial issues per patient compared to patients globally.²³

Table 13
Global Outliers for Germany
Psychosocial Issues by Gender

PSYCHOSOCIAL ISSUE	Males	Females
NOT AFFECTED	12%	
General anxiety	12%	17%
Stress related to financial issues	7%	
Disease related anxiety		35%
Sexuality		19%
LEGEND		
Negative Global Outlier for Germany		
Positive Global Outlier for Germany		

- As shown in Table 14 patients in Germany diagnosed prior to 2014 were impacted most by the fear of recurrence, disease related anxiety and by the fear of dying.
- Compared to global results, German patients diagnosed prior to 2014 were considerably less impacted overall by psychosocial issues also diagnosed at that time.
- They were also considerably less impacted by general and disease related anxiety, and by concerns about body image.
- They were notably less impacted than patients globally by isolation, stress related to financial issues and by problems getting life or health insurance.
- Patients in Germany diagnosed prior to 2014 were affected by the least number of psychosocial impacts per patient compared to patients diagnosed at that time in other countries.²⁴

²³ Further detail is available in the IKCC Global Report

²⁴ Further details available in the IKCC Global Report

Table 14
Notable Differences between Germany and Global Results
Psychosocial Issues for Patients Diagnosed Prior to 2014²⁵

PSYCHOSOCIAL ISSUE	Global	Prior to 2014	Notable Differences
NOT AFFECTED	6%	11%	5%
General anxiety	27%	14%	13%
Disease-related anxiety	56%	36%	20%
Fear of dying	38%	34%	
Fear of recurrence	50%	48%	
Depression	21%	18%	
Isolation	16%	8%	8%
Changes in relationships	27%	23%	
Difficulty on the job or in school	19%	19%	
Stress related to financial issues	21%	7%	14%
Loss or reduction in employment	20%	18%	
Difficulty navigating the healthcare system	11%	8%	
Problems getting life or health insurance	14%	5%	9%
Concerns about body image/physical appearance	22%	16%	6%
Relationships with friends/others	18%	18%	
Sexuality	18%	22%	
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- As shown in Table 15, patients who had no evidence of the disease, or who had been told they were cured, were more notably impacted than those with metastatic RCC by general anxiety and the fear of recurrence.
- Metastatic patients were impacted notably more than patients with no evidence of the disease, or who had been told they were cured, from a number of psychosocial issues listed in the Table.

²⁵ Due to insufficient data, results are not reported for patients diagnosed 2014 and after

Table 15
Notable Differences between Stage of RCC²⁶ for
Psychosocial issues in Germany

PSYCHOSOCIAL ISSUE	Metastatic RCC	No Evidence/ cured	Notable Differences
NOT AFFECTED	7%	10%	
General anxiety	9%	20%	11%
Disease-related anxiety	43%	43%	
Fear of dying	39%	33%	6%
Fear of recurrence	32%	71%	39%
Depression	16%	20%	
Isolation	16%	0%	16%
Changes in relationships	32%	20%	12%
Difficulty on the job or in school	18%	20%	
Stress related to financial issues	16%	10%	6%
Loss or reduction in employment	32%	18%	14%
Difficulty navigating the healthcare system	18%	2%	16%
Problems getting life or health insurance	9%	8%	
Concerns about body image/physical appearance	18%	18%	
Relationships with friends/others	30%	12%	18%
Sexuality	39%	16%	23%
LEGEND			
Most negative			
Most positive			

- Table 16 illustrates Global Outliers for psychosocial issues affecting patients' emotional well-being in Germany by stage.
- For example, those with no evidence of the disease, or who were told they were cured, in Germany were considerably better off overall for psychosocial issues than their peers in other countries.
- Compared to patients globally, patients in Germany with no evidence of the disease, or who had been told they were cured, were impacted by the least number of psychosocial issues per patient.²⁷

²⁶ Due to insufficient sample size, data is not available for patients with localised RCC

Table 16
Global Outliers for Germany
Psychosocial Issues by Stage²⁸

PSYCHOSOCIAL ISSUE	Metastatic RCC	No Evidence/ cured
NOT AFFECTED		10%
General anxiety	9%	20%
Disease-related anxiety	43%	
Difficulty on the job or in school	18%	
Concerns about body image/physical appearance	18%	18%
Relationships with friends/others	30%	
Sexuality	39%	
Isolation		0%
Stress due to financial issues		10%
LEGEND		
Negative Global Outlier for Germany		
Positive Global Outlier for Germany		

Patient Timeline- Most Difficult Times

- According to Table 17, German patients experienced their most difficult times during the process of diagnosis.
- Compared to patients globally, they were affected considerably more than patients in other countries by follow up scans, and by diagnosis of further disease progression.
- Compared to patients globally, German patients were less notably affected by:
 - The process of diagnosis,
 - The surveillance period, and by
 - Treatment for recurrence.

²⁷ Further detail is available in the IKCC Global Report

²⁸ Due to insufficient data results are not reported for patients with localised RCC

Table 17
Notable Differences between Germany and Global Results
Most Difficult Times for RCC Patients

MOST DIFFICULT TIME	Global	Germany	Notable Differences
NOT AFFECTED	2%	1%	
During the process of diagnosis	51%	42%	9%
Surveillance period	19%	9%	10%
Surgery & recovery afterwards	38%	36%	
Follow up scans	17%	30%	13%
Waiting for surgery or scan results	37%	34%	
Diagnosis of recurrence	21%	21%	
Treatment for recurrence	10%	4%	6%
Diagnosis of further disease progression	23%	28%	5%
Dealing with side effects of treatment	29%	31%	
Transition to palliative care	4%	3%	
Long term adjustment, survivorship	12%	10%	
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- As shown in Table 18, females in Germany were more notably affected than males by:
 - The process of diagnosis,
 - The surveillance period,
 - Follow up scans, and by
 - Waiting for surgery or scan results

- Males were affected notably more dealing with the side effects of treatment.

Table 18
Notable Differences in Germany for
Most Difficult Times by Gender

MOST DIFFICULT TIME	Males	Females	Notable Differences
NOT AFFECTED	2%	0%	
During the process of diagnosis	38%	46%	8%
Surveillance period	5%	15%	10%
Surgery and recovery afterwards	35%	38%	
Follow up scans	24%	40%	16%
Waiting for surgery or scan results	29%	42%	13%
Diagnosis of recurrence	23%	19%	
Treatment for recurrence	6%	2%	
Diagnosis of further disease progression	30%	27%	
Dealing with side effects of treatment	36%	25%	11%
Transition to palliative care	3%	2%	
Long term adjustment, survivorship	11%	10%	
LEGEND			
Most negative			
Most positive			

- Table 19 illustrates Global Outliers for patients' most difficult times in Germany by gender.
- For example, female patients in Germany were considerably worse off than female patients in other countries for follow up scans.

Table 19
Global Outliers for Germany for
Most Difficult Times by Gender

MOST DIFFICULT TIME	Males	Females
Surveillance period	5%	
Follow up scans		40%
LEGEND		
Negative Global Outlier for Germany		
Positive Global Outlier for Germany		

Communication and Support from Healthcare Professionals

- Of those patients in Germany who experienced psychosocial issues 54% said they communicated the issues to a healthcare professional, while 46% had not done so.
- In Germany:
 - 48% were very open and told the doctor everything in great detail,
 - 34% shared some of their issues, but not to the full extent,
 - 16% held back some details and minimized their symptoms and side effects or chose not to communicate their issues at all, and
 - 3% had not had the opportunity to communicate their issues at all.
- Of patients in Germany who chose to tell the doctor or everything in great detail about their psychosocial issues this was the case for:
 - 52% of male patients and 44% of female patients,
 - 50% of patients aged 46-65 yrs.²⁹, and
 - 48% of patients aged 66+ yrs. (54% globally).
- For those who communicated their issues 92% of patients found their doctors to be helpful, while this were not the case for the remaining 8%.

Barriers to Receiving Quality Care

- Patients in Germany had the following types of healthcare coverage:
 - Government healthcare (79% compared to 73% globally),
 - Private insurance (22%, compared to 39% globally),
 - Self-coverage (0%, compared to 14% globally), and
 - Family coverage (1%, compared to 6% globally).
- As Table 20 shows, 58% of patients in Germany did not experience any barriers in receiving quality care (39% globally), a notably better result than the global average.
- The lack of a locally available specialty doctor was the most notable barrier to receiving quality care.

²⁹ Due to insufficient sample sizes, data is not available for the under 46 yr. age brackets.

Table 20
Notable Differences between German and Global Results for
Barriers to Receiving Quality Care

BARRIER TO RECEIVING QUALITY CARE	Global	Germany	Notable Differences
NOT AFFECTED	39%	58%	19%
Lack of affordability, cost of treatment	21%	1%	20%
Lack of access to treatment centre (travel)	13%	8%	5%
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%	6%	12%
Lack of personal support	14%	9%	5%
No specialty doctor available locally	13%	13%	
Difficulty managing career/caregiver role while in treatment	9%	4%	
Fear of discrimination by my employer/ friends/ family	9%	6%	
No available treatments	5%	3%	
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- According to Table 21, patients in Germany 46-65 yrs. overall, experienced notably fewer barriers to receiving quality care than patients aged 66+ yrs.
- They were more notably affected by lack of access to up to date treatment/equipment, whereas those 66+ yrs. were more notably affected by lack of access to a treatment centre.

Table 21
Notable Differences in Germany for
Barriers to Receiving Quality Care by Age³⁰

BARRIER TO RECEIVING QUALITY CARE	46-65 yrs.	66+ yrs.	Notable Differences
NOT AFFECTED	60%	52%	8%
Lack of affordability, cost of treatment	1%	0%	
Lack of access to treatment centre (travel)	5%	13%	8%
Inability to understand the treatment	0%	0%	
Lack of access to up-to-date treatment/equipment	5%	0%	5%
Wait time to treatment was longer than necessary	5%	3%	
Lack of personal support	8%	10%	
No specialty doctor available locally	14%	16%	
Difficulty managing career/caregiver role while in treatment	4%	0%	
Fear of discrimination by my employer/ friends/ family	5%	6%	
No available treatments	4%	0%	
LEGEND			
Most negative			
Most positive			

- Table 22 illustrates Global Outliers for barriers to receiving quality care in Germany by age.
- For example, German patients aged 46+ yrs. were considerably better off for the lack of access to the most up to date treatments than patients aged 46+ yrs. in other countries.
- Patients in Germany aged 46-65 yrs. experienced the least number of barriers to receiving quality care per patient than their counterparts in other countries.³¹

³⁰ Due to insufficient sample size, data is not reported for under 46 yr. age brackets.

³¹ Further details are available in the IKCC Global Report

Table 22
Global Outliers for Germany for
Barriers to Receiving Quality Care by Age³²

BARRIER TO RECEIVING QUALITY CARE	46-65 yrs.	66+ yrs.
Lack of access to most up-to-date treatment/equipment	5%	0%
Wait time to treatment longer than necessary	5%	
LEGEND		
Negative Global Outlier for Germany		
Positive Global Outlier for Germany		

- As Table 23 indicates, overall, female patients in Germany were notably more affected by barriers to receiving quality care than male patients, and for lack of personal support.
- Male patients were notably more affected than females by lack of access to a treatment centre.

³² Due to insufficient data, results are not reported for patients under 46 yrs.

Table 23
Notable Differences in Germany for
Barriers to Receiving Quality Care by Gender

BARRIER TO RECEIVING QUALITY CARE	Males	Females	Notable Differences
NOT AFFECTED	63%	50%	13%
Lack of affordability, cost of treatment	0%	2%	
Lack of access to treatment centre (travel)	13%	2%	11%
Inability to understand the treatment	0%	0%	
Lack of access to up-to-date treatment/equipment	5%	4%	
Wait time to treatment was longer than necessary	5%	8%	
Lack of personal support	5%	15%	10%
No specialty doctor available locally	13%	13%	
Difficulty managing career/caregiver role while in treatment	3%	6%	
Fear of discrimination by my employer/ friends/ family	5%	8%	
No available treatments	3%	2%	
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- Table 24 illustrates Global Outliers for barriers to receiving quality care in Germany by gender.
- For example, males in Germany were considerably better off for wait times to treatment than male patients in other countries.

Table 24
Global Outliers for Germany
Barriers to Receiving Quality Care by Gender

BARRIER TO RECEIVING QUALITY CARE	Males	Females
Wait time to treatment longer than necessary	5%	
Lack of access to treatment centre/travel		2%
LEGEND		
Negative Global Outlier for Germany		
Positive Global Outlier for Germany		

- As shown in Table 25, patients with clear cell RCC were more notably affected than patients with other sub-types by lack of locally available specialty doctors.
- Those with other sub-types were more notably affected than clear cell patients by wait times to treatment, and by lack of personal support.

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

BARRIER TO RECEIVING QUALITY CARE	Clear Cell	Other sub-types	Notable Differences
NOT AFFECTED	59%	60%	
Lack of affordability, cost of treatment	0%	3%	
Lack of access to treatment centre (travel)	5%	7%	
Inability to understand the treatment	0%	0%	
Lack of access to up-to-date treatment/equipment	3%	7%	
Wait time to treatment was longer than necessary	5%	10%	5%
Lack of personal support	8%	13%	5%
No specialty doctor available locally	16%	10%	6%
Difficulty managing career/caregiver role while in treatment	3%	3%	
Fear of discrimination by my employer/ friends/ family	7%	3%	
No available treatments	3%	3%	
LEGEND			
Most negative			
Most positive			

- Table 26 illustrates Global Outliers for barriers to receiving quality care in Germany by sub-type.
- For example, patients with other sub-types in Germany were affected considerably less than patients with other sub-types globally by lack of access to up to date treatment and by the fear of discrimination.
- Patients in Germany with both clear cell and those with other sub-types were affected by the least number of barriers to receiving quality care per patient³³ compared to their counterparts in other countries.

³³ For further detail, see the IKCC Global Report

Table 26
Global Outliers for Germany for
Barriers to Receiving Quality Care by Sub-type

BARRIER TO RECEIVING QUALITY CARE	Clear Cell	Other Sub-types
Lack of access to up-to-date treatment/equipment		7%
Fear of discrimination by employer/friends/family		3%
LEGEND		
Negative Global Outlier for Germany		
Positive Global Outlier for Germany		

V. Opportunities to Improve Care

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

Surveillance

- At the time of the survey, patients in Germany were in the following stages of their RCC:
 - 3% were in Stage 1 or 2 (13% globally),
 - 3% in Stage 3 (8% globally),
 - 39% in Stage 4,
 - 21% had no evidence of the disease,
 - 20% had been told they were cured (a Global Outlier, compared to 10% globally), and
 - 10% had died (a Global Outlier, compared to 4% globally).

- Their last follow up scan had occurred:
 - Less than one year ago (82%),
 - 1-3 years ago (11%), 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 4³⁴,
 - 2% of those who had no evidence of the disease, or had been told they were cured,
 - 17% of those who had died (a Global Outlier, compared to 27% globally),

 - 3% of those aged 46-65³⁵,
 - 3% of those aged 66+ yrs.,

 - 3% of males,
 - 2% of females,

 - 0% of those with no understanding of kidney cancer guidelines, and
 - 0% of those with no understanding of the guidelines for kidney cancer follow up.

³⁴ Due to insufficient data, results are not reported for Stages 1, 2 or 3

³⁵ Due to insufficient data, results are not reported for under 46 yr. age bracket

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 Germany 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.

25% of patients in Germany had their treatment plans decided for them solely by their doctors. This was particularly the case for middle aged patients and those in later stages of their disease.

- 25% of patients in Germany were not engaged at all in their treatment plans, in that their doctor decided their treatment plan solely for them.
- Of those patients who were involved in their treatment decision:
 - 8% made the decision by themselves,
 - 62% made a joint decision with their doctors (51% globally), and
 - 4% were asked for input from their doctors (a Global Outlier, compared to 12% globally).
- The following helped German patients with their treatment plans:
 - Partner/spouse (42% a Global Outlier, compared to 56% globally),
 - Parents (3% a Global Outlier, compared to 13% globally),
 - Children (10% a Global Outlier compared to 21% globally),
 - Friends/other family members (6% a Global Outlier, compared to 20% globally),
 - Local family doctor (26%), and
 - A patient organisation (13%).
- 29% of patients made the decision by themselves (a Global Outlier, compared to 18% globally), and for 0%, the decision rested on their personal financial situation.

- In the case where treatment plans were decided solely by the doctor without any input from the patient this affected:³⁶
 - 28% of those aged 46-65 yrs.,
 - 15% of those aged 66+ yrs. (27% globally),

 - 26% of those in Stage 4³⁷,
 - 29% of those who had no evidence of the disease or who were told they were cured,
 - 17% of those who had died (29% globally).

 - 21% of males (28% globally),
 - 31% of females, and

 - 22% of patients of those diagnosed prior to 2016 (compared to 28% globally).

³⁶ Due to insufficient sample size, data is not reported for the under 45 yr. age brackets.

³⁷ Due to insufficient sample sizes, data is not available for patients in Stages 1, 2 or 3.

Acknowledgements

This report was prepared by Perception Insight on behalf of the International Kidney Cancer Coalition (IKCC.org). The IKCC wishes to thank the members of the Global Patient Survey Steering Committee and all Affiliate Organisations for their collaboration on this project.

This project was funded by Bristol-Myers Squibb, Ipsen Pharma, Novartis and Pfizer according to the IKCC Code of Conduct Governing Corporate Funding (ikcc.org). Sponsors have not been involved in the design or analysis of the survey results. This report is entirely the product of Perception Insight, an independent arms-length global market research company and is copyrighted by Perception Insight and the International Kidney Cancer Coalition.

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

Table 1 Notable Differences for Time of Diagnosis by Gender.....	11
Table 2 Notable Differences for Time of Diagnosis by Age	12
Table 3 Lack of Patient Understanding at Time of Diagnosis by Sub-type.....	13
Table 4 Notable Differences between Place of Treatment for Patient Initial and Subsequent Treatments in Germany.....	22
Table 5 Notable Differences between Germany and Global Results for Physical Conditions	24
Table 6 Notable Differences in Germany for Physical Conditions by Gender	25
Table 7 Global Outliers for Germany Physical Conditions by Gender	26
Table 8 Notable Differences between Germany and Global Results Physical Conditions for Patients Diagnosed Prior to 2014	27
Table 9 Notable Differences in Germany for Physical Conditions by Stage	28
Table 10 Global Outliers for Germany Conditions Affecting Physical Well-being by Stage.....	29
Table 11 Notable Differences between Germany and Global Results for Psychosocial Issues	30
Table 12 Notable Differences in Germany for Psychosocial Issues by Gender	31
Table 13 Global Outliers for Germany Psychosocial Issues by Gender	32
Table 14 Notable Differences between Germany and Global Results Psychosocial Issues for Patients Diagnosed Prior to 2014	33
Table 15 Notable Differences between Stage of RCC for Psychosocial issues in Germany.....	34
Table 16 Global Outliers for Germany Psychosocial Issues by Stage.....	35
Table 17 Notable Differences between Germany and Global Results Most Difficult Times for RCC Patients	36
Table 18 Notable Differences in Germany for Most Difficult Times by Gender	37
Table 19 Global Outliers for Germany for Most Difficult Times by Gender.....	37
Table 20 Notable Differences between German and Global Results for Barriers to Receiving Quality Care.....	39
Table 21 Notable Differences in Germany for Barriers to Receiving Quality Care by Age	40
Table 22 Global Outliers for Germany for Barriers to Receiving Quality Care by Age	41
Table 23 Notable Differences in Germany for Barriers to Receiving Quality Care by Gender	42
Table 24 Global Outliers for Germany Barriers to Receiving Quality Care by Gender	42
Table 25 Notable Differences in Germany for Barriers to Receiving Quality Care by Sub-Type.....	43
Table 26 Global Outliers for Germany for Barriers to Receiving Quality Care by Sub-type	44