



European Association of Urology



## Brief Correspondence

# Patient-reported Experience of Diagnosis, Management, and Burden of Renal Cell Carcinomas: Results from a Global Patient Survey in 43 Countries

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### Abstract

The International Kidney Cancer Coalition (IKCC) is a federation of 46 affiliated patient organisations representing 1.2 million patients worldwide that is committed to reducing the global burden of kidney cancer. A large-scale global survey of patients with renal cell carcinoma (RCC) to capture real-world experiences has never been undertaken. The 35-question survey was designed to identify geographic variations in patient education, experience, awareness, access to care, best practices, quality of life, and unmet psychosocial needs. A total of 1983 responses were recorded from 43 countries in 14 languages. Analysis revealed key findings. (1) At diagnosis, 43% of all respondents had no understanding of their RCC subtype. (2) Shared decision-making remains aspirational: globally, 29% of all patients reported no involvement in their treatment decision, responding “My doctor decided for me”. (3) While 96% of respondents reported psychosocial impacts, surprisingly, only 50% disclosed them to their health care team. (4) Lastly, 70% of patients were not asked to participate in a clinical trial, although 90% indicated they would be interested. The survey reflects patient perspectives from diverse clinical scenarios in which different treatment options are available. The data point to actionable deficits in the fields of clinical trials, psychosocial support, and shared decision-making.

**Patient summary:** In this brief report, we highlight the key results from the first large-scale global survey of patients with kidney cancer to capture real-world experiences. This survey reflects patient perspectives from diverse clinical scenarios in which different treatment options are available. We conclude that there is a need for improvement in the fields of clinical trials, psychosocial support, and shared decision-making.

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Kidney cancer (renal cell carcinoma, RCC) is the seventh most common cancer and has shown a sustained increase

in global prevalence, thereby presenting an increasing burden on health systems, governments, and, most of all,



individual patients and their families [1–3]. Although therapies have improved for both early-stage and late-stage RCC, little is known about variations in the patient experience and best practices among countries. Although many individual national surveys by patient organisations [4,5] have been conducted over the years, they either focused on one particular aspect of psychological wellbeing (eg, distress or fear of recurrence) or were not peer-reviewed and published in the literature, and no conclusions could be drawn about country-level variations in patient experience or best practice. Other examples of patient-reported surveys in the literature include those that measure physical health and quality of life [6] but these did not prioritise the unmet needs of this group across the care pathway. Here we report on the first global patient survey on the diagnosis, management, and burden of RCC conducted by the International Kidney Coalition (IKCC) and involving its affiliate organisations worldwide. The aim of the survey, which was administered in 14 languages, was to improve our collective understanding and to contribute towards reducing the burden of kidney cancer around the world.

The 35-question survey on the diagnosis, management, and burden of RCC was designed by a multinational steering committee of patient leaders, urologists, medical oncologists, and an academic health psychologist to identify geographic variations in the prioritisation of issues in six key dimensions. These were: patient education, experience, and awareness; access to care; access to clinical trials, best practices; quality of life; and unmet psychosocial needs. These were chosen on the basis of the most frequently reported question in the literature, and included dimensions of emotional functioning and quality of life such as anxiety, depression, fear, isolation, financial worries, relationships, and sexuality. The aim was to identify and prioritise unmet needs rather than to measure emotional functioning and quality of life. Where possible, questions followed the Likert 4- or 5-point response format, and no open questions were posed.

The survey was not assessed by an ethics committee. The survey was distributed to patients with kidney cancer and their caregivers in 14 languages (including UK and US English, French and Canadian French, and Portuguese and Brazilian Portuguese) through 30 of the IKCC affiliate organisations and social media. It was completed online or in paper form by kidney cancer patients or their caregivers responding about the patient experience (September to October 2018) using QuestionPro, a third-party consultant for data protection. To avoid duplicate responses, completed surveys were linked to a unique receipt number, and internet service provider addresses were manually checked for single use, followed by enquiry if multiple uses were detected. To evaluate intercountry variation,  $\chi^2$  tests were performed, with the null hypothesis being that there were no differences between countries.

A total of 1983 responses were recorded from 43 countries in 14 languages (online,  $n = 1862$ ; on paper,  $n = 121$ ; Table 1). Of the 1983 respondents, nearly half were from Canada, France, the USA, or South Korea (12% each), 10% were from Japan, 9% were from the UK, 7% were from India and Mexico, and 6% were from Germany; the remaining 34

countries each accounted for <5% of the respondents. The survey results were analysed using cross-tabulations by an independent third-party organisation. The full global report is publicly available, as well as nine individual country reports for countries from which at least 100 responses were received (Canada, France, Germany, India, Japan, Mexico, South Korea, UK, USA) [7]. The rate of missing data was 16%. Three key findings highlighted by the results are understanding of diagnosis, participation in clinical trials, and discussion of psychosocial impact (Fig. 1). Globally, we compared the answers provided by caregivers with those from the patients in a post hoc analysis, and found no outstanding differences between the two groups; however, discrepancies at country levels may have been overlooked.

The survey results suggest there is a notable lack of understanding of diagnosis, stage, and subtype among the participants. Globally, 38% of respondents reported that they were not told the subtype of their RCC at diagnosis, which is critical for treatment decision-making. Furthermore, 20% of respondents reported that they had no understanding of their stage and 43% had no understanding of their subtype (for reporting purposes, subtypes have been categorised into “clear cell RCC” and “other subtypes” which include all other subtypes reported by respondents).

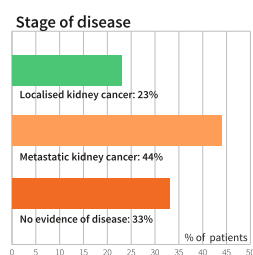
This lack of understanding also included treatment options and prognosis. Some 21% of respondents indicated that they had no understanding of their treatment options, 19% had no understanding of their treatment recommendations, 28% had no understanding of the risk of recurrence, and 25% had no understanding of their likelihood of survival.

Patients in Germany reported the least understanding of any country surveyed for various aspects of their disease

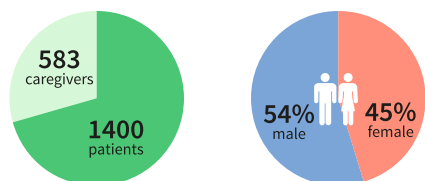
**Table 1 – Patient characteristics**

Parameter	Result
Participants, $n$ (%)	1983 from 43 countries
Patients	1400 (71)
Caregivers	583 (29)
Gender (%)	
Male	54
Female	45
Prefer to self-describe	1
Age category (%)	
<18 yr	1
18–29 yr	2
30–45 yr	20
46–65 yr	57
≥66 yr	20
Renal cell carcinoma subtype (%)	
Clear cell	74
Papillary	6
Chromophobe	5
Transitional cell	<1
Unclassified	4
Benign growth	1
Renal sarcoma	<1
Renal medullary	<1
Xp11 translocation	1
Collecting duct	1
Wilm's tumour	1
Other	4

**A Demographics**



**B Participants**



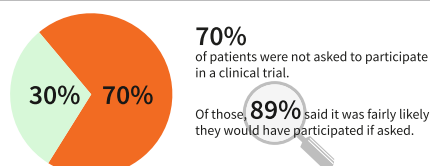
**C Understanding of diagnosis**

Understanding their individual diagnosis, including kidney cancer subtype, helps patients evaluate treatment options, clinical trials, and long-term surveillance plans.

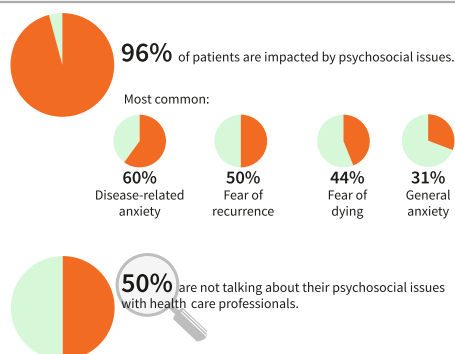
Yet patients reported:



**D Participation in clinical trials**



**E Discussion of psychosocial impact**



**Fig. 1 – Summary of the key findings from the study.**

and care, while patients in France and Mexico reported the best understanding for all aspects of their RCC.

The survey results suggest that the global health care community has not been proactive in approaching RCC patients about their possible participation in clinical trials. Of all patients, 70% had never been asked to participate in a clinical trial. However, 89% of those never asked reported that they would be fairly likely to participate in a clinical

trial if asked, particularly if provided with the necessary information to make the decision. Of those who were asked, their high rate of participation and degree of satisfaction with the experience indicate an obvious lost opportunity to improve the quality of care and survivorship of RCC patients through research. Interestingly, patients in Germany reported the most reasons per patient why they were not willing to participate in a clinical trial and, notably, a considerable distrust of clinical trials when compared to patients in other countries. By contrast, there is a particularly notable missed opportunity in Japan, where 91% of patients had never been asked to participate in a clinical trial and yet they reported the highest likelihood of participation should they be asked.

Our survey found a high psychosocial burden of kidney cancer (96%) and inadequate discussion of this negative impact with health care professionals. For those living with localised kidney cancer, the top three concerns were disease-related anxiety (53%), fear of recurrence (50%), and fear of dying (43%). For those living with metastatic kidney cancer, the top three were disease-related anxiety (67%), fear of dying (51%), and changes in relationship status (35%). Stress related to financial issues, depression, and generalised anxiety were also key issues for both groups. Reports of psychosocial distress and sources of concern varied significantly by country. For example, there were extreme variations between Japan and Mexico regarding fear of recurrence (67% vs 40%) and fear of dying (59% vs 32%). Patients in the USA reported the greatest number of psychosocial issues. All of these issues could be addressed through the design and delivery of appropriate and supportive cancer care. However, disclosure of psychosocial issues and/or appropriate discussion with health care professionals is needed to facilitate such supportive care. Surprisingly, only 50% of global respondents disclosed these psychosocial issues to their health care team, which is also actionable. There was significant country-level variation, with French patients being more likely and patients in South Korea and Japan less likely to disclose psychosocial issues to their health care team.

The study has a number of limitations. (1) This was a hypothesis-generating prospective survey and therefore we could not validate or counter a predetermined hypothesis. (2) We were unable to compare online versus on-paper responses, because on-paper responses constituted the vast majority of responses from India (121/140 responses) and we did not have on-paper responses submitted from any other country. (3) There is an inherent bias introduced since the survey was promoted via patient organisations, perhaps over-representing patients active in patient organisations. (4) There is probably underestimation of outcomes for RCC patients who are old, alone, and/or have low socioeconomic status with limited access to the survey. (5) Some discrepancies between patients and caregivers when reporting unmet needs or problems might not have been adequately captured.

This research sheds light on unmet needs in the RCC patient experience and highlights actionable improvements to the design and delivery of supportive care. This first-ever global survey of nearly 2000 people affected by kidney can-

cer serves as a benchmark for biennial longitudinal data collection and could be used to inform future disease-specific quality-of-life instruments. For example, a deeper analysis of how physical health was maintained in Japanese patients and the relative success with psychological health and psychosocial interventions reported by patients in India might deliver best-practice insights. French patients overall and German patients aged 30–45 yr or with a rare kidney cancer subtype experienced the least number of barriers to care in comparison to the global results. These results could all be pointers to focus research and to help in improving the quality of care for kidney cancer patients worldwide.

**Author contributions:** Sara MacLennan had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

**Study concept and design:** Giles, Maskens, Bick, Martinez, Packer, Heng, Larkin, Bex, Jewett, Jonasch, MacLennan.

**Acquisition of data:** Giles, Maskens.

**Analysis and interpretation of data:** Giles, Maskens, MacLennan.

**Drafting of the manuscript:** Giles, Maskens, MacLennan.

**Critical revision of the manuscript for important intellectual content:** Giles, Maskens, Heng, Larkin, Bex, Jewett, Jonasch, MacLennan.

**Statistical analysis:** Giles, Maskens, MacLennan.

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