Global Patient Survey:
Reported Experience of Diagnosis, Management, and Burden of Renal Cell Carcinomas:

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Abstract

Background: Kidney cancer (renal cell carcinoma, RCC) is now the 7th most common cancer. The sustained increase in global prevalence has increased the burden to health systems, and most of all, to individual patients and their families. Little is known about the variations in the patient experience and best practices among countries. Here, we report on the 3rd biennial Global Patient Survey on the diagnosis, management, and burden of RCC. Conducted by the International Kidney Cancer Coalition (IKCC) and involving its Affiliate Organisations worldwide, the survey aims to improve collective understanding and to contribute toward the reduction of the burden of kidney cancer around the world. **Methods:** A 35-question survey on the diagnosis, management, and burden of RCC was designed by a multi-country steering committee of patient leaders to identify geographic variations in 6 key dimensions: patient education, experience and awareness, access to care and clinical trials, best practices, quality of life, and unmet psychosocial needs. The survey was distributed in 13 languages to patients with kidney cancer and their caregivers, through IKCC's 49 Affiliate Organisations and social media. It was completed online or in paper form between 29 Sept - 21 Nov 2022.

Patient Characteristics

2,213 responses from **39** countries

Patient Characteristics

- 1655 patients
- 547 carers
- 11 undisclosed

✓ **54% male, 44% female, 2% did not wish to identify**

✓ **59% between ages 46-55, 22% ages 30-45, 13% >65 years old**

✓ **11% localised disease, 42% NED, 47% advances/metastatic**

✓ **58% ccRCC, 21% pRCC, 4% chromophobe, 1% VHL, 1% Xp11 translocation, 1% benign, 1% renal medullary carcinoma, 3% don't know, 2% unclassified**

✓ **39% diagnosed between 2020-present, 24% between 2017-2019, 20% between 2010-2016, 17% prior to 2010**

TOPLINE RESULTS:

IKCC International Kidney Cancer Coalition

48% of those with greatest risk of hereditary RCC are not being considered or counseled appropriately

35% of respondents reported they had been asked to consider participating in a cancer clinical trial

70% agreed to participate in the cancer clinical trial

65% reported they were very satisfied or satisfied with their overall experience of the cancer clinical trial

20% felt their sense of emotional wellbeing since their diagnosis has always been impacted by disease-related anxiety

28% reported fear of recurrence always impacts their sense of emotional wellbeing since their diagnosis

11% reported always feeling their sense of emotional wellbeing since their diagnosis being impacted by sadness or depressi

CONCLUSIONS

•The survey identified several actionable deficits, including lost opportunities in genetic testing

•This third-ever global survey confirmed previous data pointing to lack of understanding about the disease, genetic testing among patients at risk, clinical trials, and psychosocial impact, while delivering novel data about patient perspectives concerning biopsies, physical activity, and follow up scheduling.

•RWE indicates opportunities to improve communication about diagnosis, psychosocial impacts, and clinical trials

Conflict of Interest

This project was funded with sponsorship from the following companies in full compliance with the IKCC Code of Conduct: BMS, Eisai, Exelixis, Ipsen & MSD*. Data was independently analyzed by the Picker Institute. **Partial sponsor*

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