

# Patient-Reported Experience of Diagnosis, Management, and Burden of Renal Cell Carcinomas: Results from a Global Patient Survey in 41 countries

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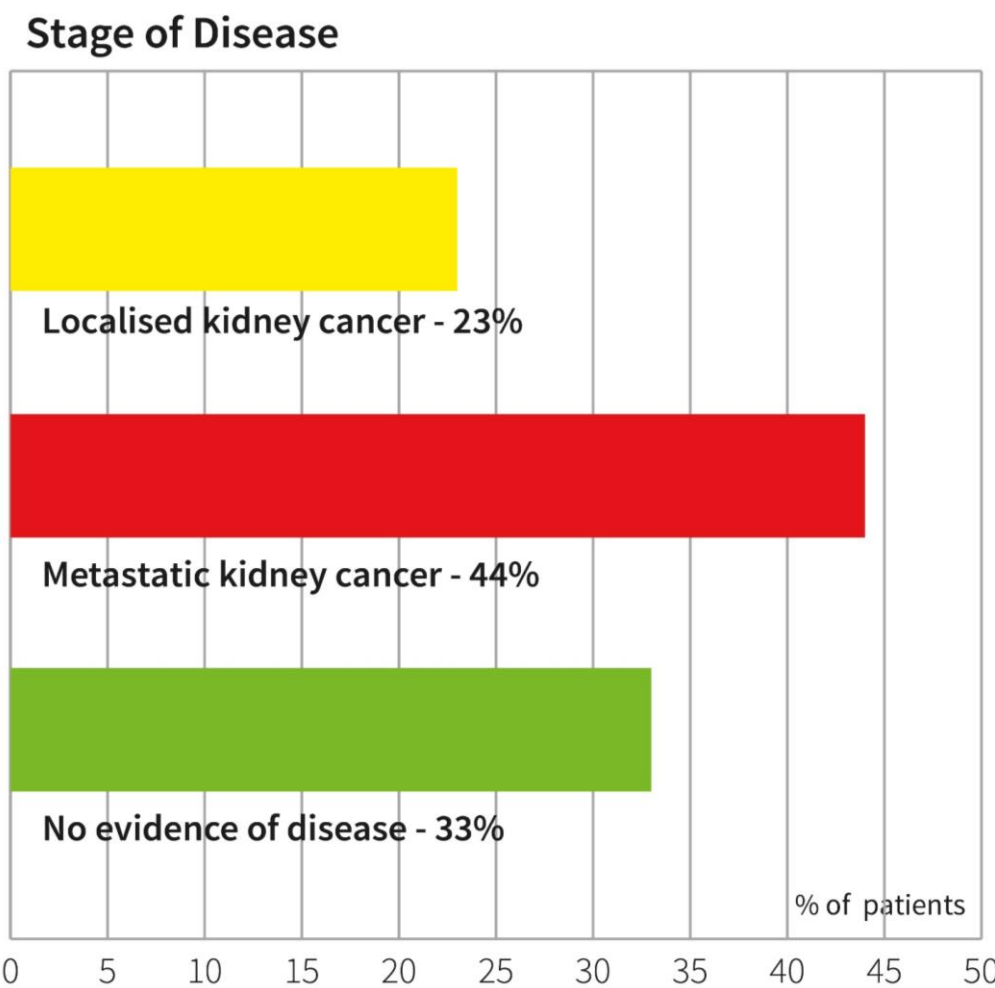
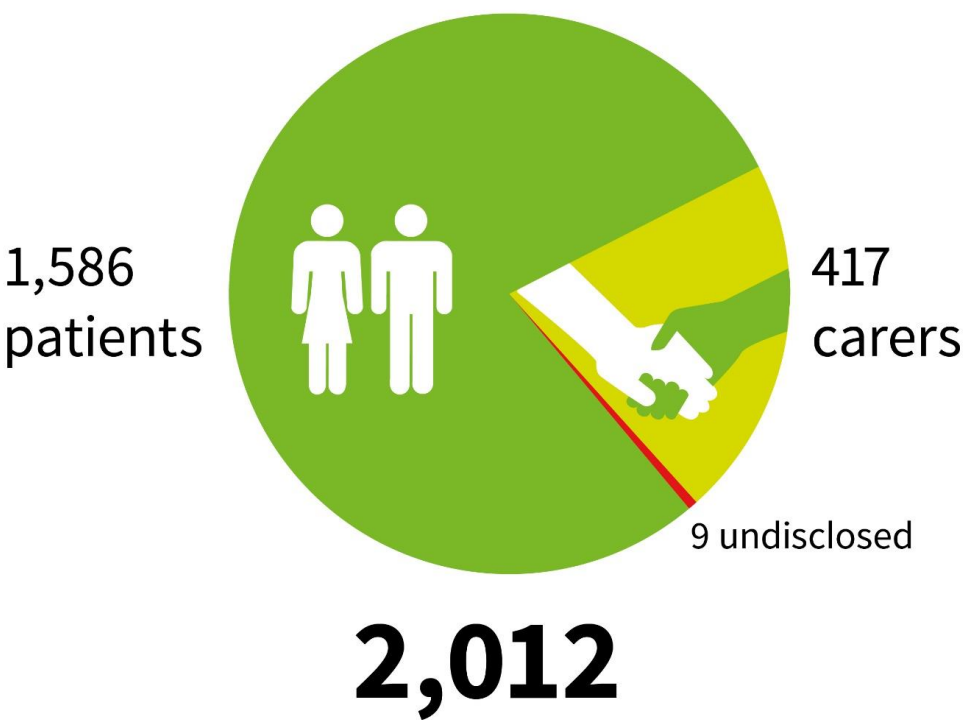
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## Abstract

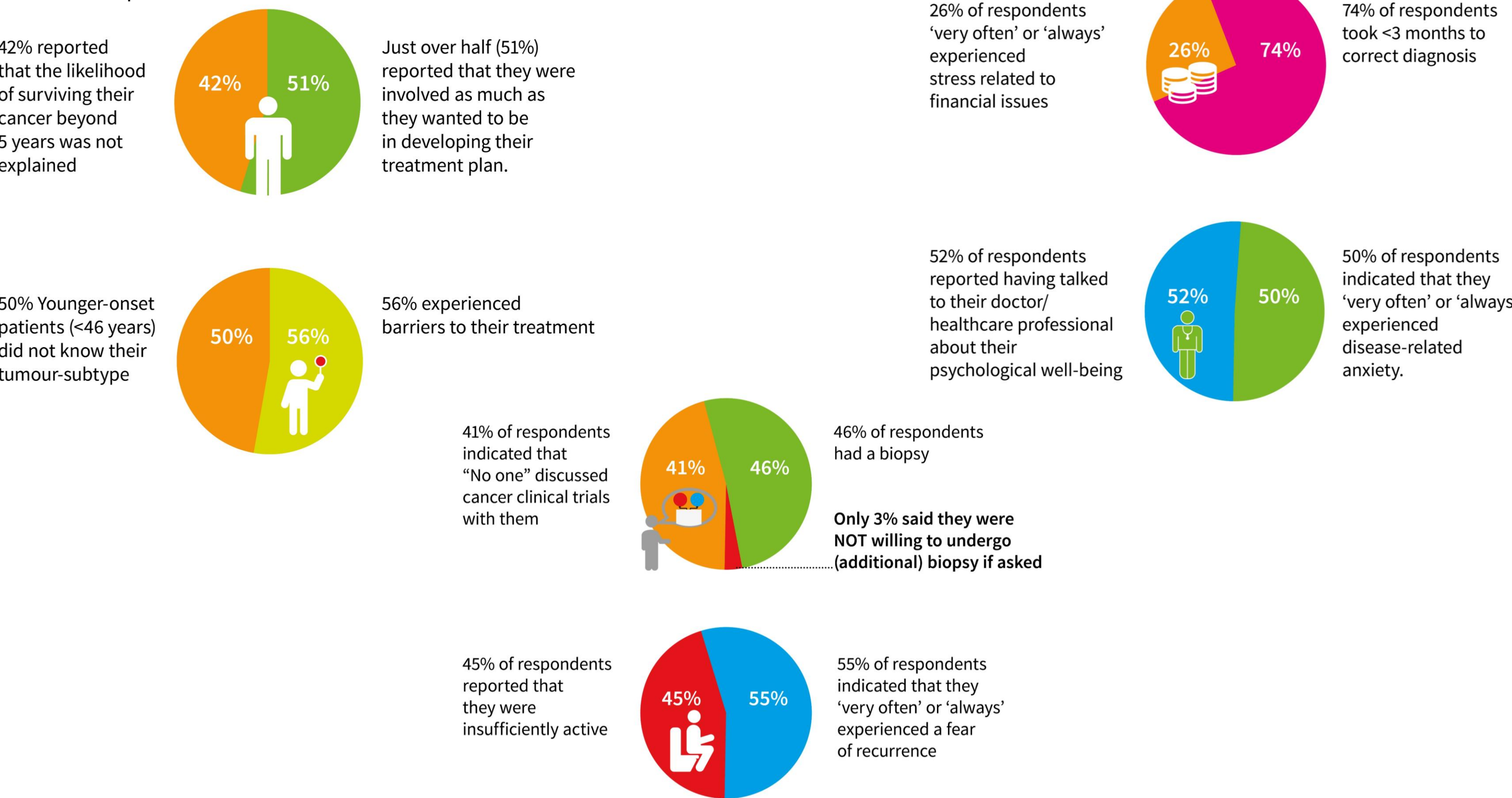
**Background:** Kidney cancer (renal cell carcinoma, RCC) is now the 7th most common cancer. The sustained increase in global prevalence has increased the burden to health systems, and most of all, to individual patients and their families. Little is known about the variations in the patient experience and best practices among countries. Although individual national surveys have been held, no conclusions could be drawn about country-level variation in patient experience or best practice. Here, we report on the 2nd 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 46 Affiliate Organisations and social media. It was completed online or in paper form between 29 Oct 2020 and 5 Jan 2021.

## Patient and Survey Characteristics



## RESULTS

2,012 (1,586 patients, 417 caregivers, 9 undisclosed) responses were recorded from 41 countries in 13 languages. Survey results were analysed using cross-tabulations by an independent third-party organisation. The full global report will be publicly available, as well as 7 individual country reports where at least 100 responses were received.



## CONCLUSIONS

- The survey identified several actionable deficits.
- This second-ever global survey confirmed previous data pointing to lack of understanding about the disease, clinical trials, and psychosocial impact, while delivering novel data about patient perspectives concerning biopsies, physical activity, and patient engagement .
- RWE indicates opportunities to improve communication about diagnosis, psychosocial impacts, and clinical trials, as well as biopsies, physical exercise, and patient engagement..

## Conflict of Interest

This project was funded with sponsorship from the following companies in full compliance with the IKCC Code of Conduct: BMS, Ipsen, Merck KGaA, and Pfizer. Data was independently analyzed the Picker Institute