

Global Patient Survey Fact Sheet

The International Kidney Cancer Coalition's Global Patient Survey is a biennial survey designed to identify geographic variations in patients' education, experience and awareness. Specifically, the survey aims to highlight best practices and unmet needs related to patients' access to care, quality of life and involvement in clinical trials.

Launched in 2018 in a partnership between IKCC and its network of Affiliate Organisations the online survey was completed in 14 languages by 1983 patients and carers from 43 countries worldwide.

Results of the survey help inform IKCC's strategic priorities and activities. They have also been widely shared at international and regional oncology conferences.

2018 Survey Highlights

- At the time of their diagnosis, patients had no understanding of their: subtype (43%); risk of recurrence (28%); their likelihood of survival (25%); or their treatment options (21%).
- 92% of respondents said their physical well-being was impacted since their initial diagnosis. Most common conditions included:
 - Fatigue – 66%
 - Bowel changes – 33%
 - Muscle weakness – 32%
 - Sleeplessness – 31%
- 96% of patients said they were impacted by psychosocial issues. Most common conditions included:
 - Disease-related anxiety – 60%
 - Fear of recurrence – 50%
 - Fear of dying – 44%
 - General anxiety – 31%
- 70% of patients had never been asked to participate in a clinical trial. Of those, 89% said it was fairly likely they would have participated if they had been asked.

The complete results of the Global Patient Survey for 2018, including graphics, can be viewed [here](#).

For more information about the Global Patient Survey, contact Julia Black at julia@ikcc.org.