The survey included 1983 respondents in 43 countries.

The Global Patient Survey included respondents from Canada (12%), France (12%), the United States (12%), South Korea (12%), Japan (10%), the United Kingdom (9%), Mexico (7%), India (7%), Germany (6%), Brazil (3%), The Netherlands (2%), Australia (2%), Finland (2%), Other (4%).

583 carers
1400 patients

Participants

54%
45%

Gender

Stage of Disease

Localised kidney cancer - 23%
Metastatic kidney cancer - 44%
No evidence of disease - 33%

Knowledge and Understanding

At the time of diagnosis, patients had no understanding of their:

- Subtype - 63%
- Risk of recurrence - 28%
- Likelihood of survival - 25%
- Treatment options - 21%
- Stage of cancer - 20%
- Treatment recommendation - 19%

Physical Conditions

92% of patients said their physical well-being was impacted since the initial diagnosis.

Most common conditions included:

- Fatigue - 66%
- Bowel changes - 33%
- Muscle weakness - 32%
- Sleeplessness - 31%

Psychosocial Conditions

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%
Global Patient Survey 2018: Mapping the Kidney Cancer Patient Experience Worldwide
Snapshot

**Clinical Trials**

30% of patients were asked to participate in a clinical trial.

Of those asked, 86% agreed and the majority were satisfied with their experience.

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.

45% of these patients were being treated in a major cancer centre and 37% at a local or community hospital.

**Patients discussed clinical trials with their:**

- Doctor - 88%
- Family and friends - 31%
- Patient organisations - 18%
- Online groups - 16%
- Nurse - 15%
- Another patient - 9%
- Didn’t discuss with anyone - 2%

Patients of all stages were not involved in their treatment decisions:
- 25% were stage 1 or 2
- 20% were stage 3
- 30% were stage 4.

**Shared Decision Making**

71% of patients were involved in their treatment decisions to some degree.

29% of patients were not engaged in their treatment decisions at all.

**Where were they treated?**

Of patients who reported “my doctor decided for me”
- 34% were treated in a community or local hospital and
- 45% in a major cancer centre.

**What stage was the cancer?**

Patients of all stages were not involved in their treatment decisions:
- 25% were stage 1 or 2
- 20% were stage 3
- 30% were stage 4.


We need to talk about Kidney Cancer.