IKCC’s Global Patient Survey on kidney cancer is designed to identify geographic differences in patients’ experiences, to highlight best practices and unmet needs related to patients’ access to care, assess quality of life, determine the prevalence of shared decision-making, and survey involvement in clinical trials. The biennial survey helps understand how the patient experience is changing over time.

**Current Stage of Disease**

- Localised kidney cancer - 11%
- Advanced/metastatic kidney cancer - 47%
- No evidence of disease - 42%

**Knowledge and Understanding**

When people know more about their diagnosis, they are more informed and empowered to participate in decisions about their treatment and care. In addition, knowing more can also help reduce uncertainty, which can have a positive effect on a person’s well-being.

The following were not explained to patients in a way they could understand:

- Likelihood of survival beyond 5 years - 42%
- Subtype - 32%
- Risk of recurrence - 29%
- Stage of cancer - 14%
- Treatment options - 11%
- Treatment recommendations - 9%

**Shared Decision-Making**

Were you involved as much as you wanted to be in decisions about your treatment plan?

- Yes, definitely – 48%
- Yes, to some extent – 37%
- No – 15%

Despite that shared decision-making is accepted as an important pillar of patient engagement, the number of people who are not as involved in their treatment decisions as they want to be has not changed.

For more information, visit www.IKCC.org/global-patient-survey.

© IKCC = International Kidney Cancer Coalition 2022

This project was funded with sponsorship from the following companies in full compliance with the IKCC Code of Conduct: Astra Zeneca, BMS, Exelixis, Ipsen, MSD* Roche, Telix* (*Partial Funding)
We need to talk about: **Quality of Life**

With more open dialogue about concerns, fears, and impacts on daily living, people can better understand what to expect and learn about available resources, which can lead to overall improved quality of life. However, it is equally important for physicians and allied healthcare teams to consider patients’ psychological health, by evaluating it and supporting treatment.

We need to talk about: **Genetic Testing**

The chances of a kidney cancer being hereditary increases when the cancer is diagnosed in someone 46 years or younger, there is a family history of kidney cancer or the patient has bilateral disease. If an individual meets any of these criteria, they should be offered genetic testing.

We need to talk about: **Clinical Trials**

It is through clinical trials – and the patients who take part in trials for new treatments – that makes advances in treatment and care possible.

When asked why a patient agreed to participate in a clinical trial, 60% said because their doctor recommended it, 50% thought it might offer better care and 43% wanted to help research.