

# Global Patient Survey 2018: Mapping the Kidney Cancer Patient Experience Worldwide

## Highlights Report



**We need to talk about Kidney Cancer.**

# We need to talk about: **Kidney Cancer**

Kidney cancer is a serious disease that affects hundreds of thousands of people worldwide. Incidence is on the rise globally. In fact, the International Agency for Research on Cancer projects a 22% increase from 338,000 in 2012 to 413,000 cases annually by 2020<sup>1</sup>.

The International Kidney Cancer Coalition (IKCC) is a global collaboration of patient organisations focused on reducing the burden of kidney cancer worldwide. Since inception in 2009, through the IKCC we have been working together to improve patients' experience through advocacy, awareness, education and research.

In 2018, IKCC Affiliate Organisations came together to recognise and address an evidence gap in research about the kidney cancer patient experience worldwide. We sought to

benchmark and measure the real-world experiences of patients and carers related to kidney cancer diagnosis, knowledge, quality of life and clinical trials.

Launched in 2018, this first Global Patient Survey has examined geographic variations and global themes related to the kidney cancer experience. By assessing global variations and country specific-data, we have identified both best practices and the gaps that need urgent attention.

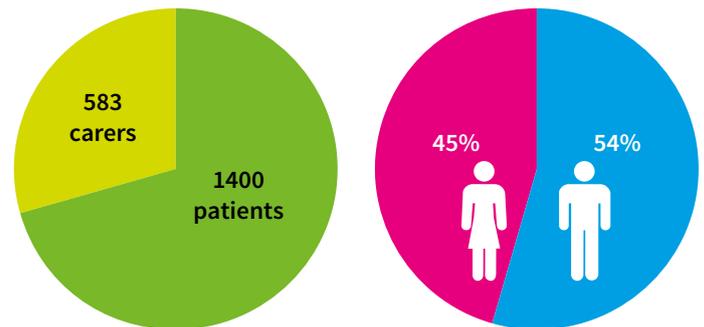
We invite you to explore highlights of IKCC's Global Patient Survey in this report. And while limitations have been identified, we are energized by the opportunities presented to improve the lives of patients worldwide. What has become abundantly clear is that we need to talk about kidney cancer.

*The Global Patient Survey Steering Committee*

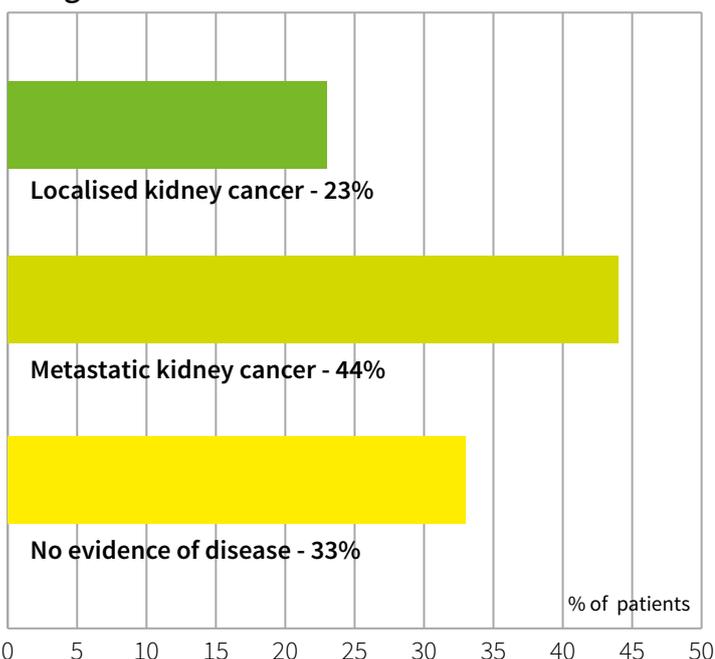
## Demographics

The survey included **1983** respondents in **43** countries.

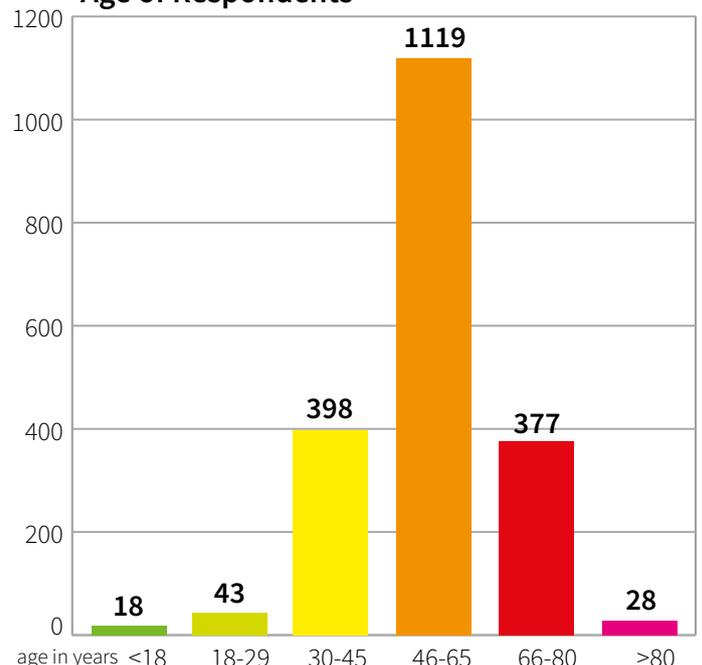
The Global Patient Survey included respondents from Canada (12%), France (12%), the United States (12%), South Korea (12%), Japan (10%), the United Kingdom (9%), Mexico (7%), India (7%), Germany (6%), Brazil (3%), The Netherlands (2%), Australia (2%), Finland (2%), Other (4%).



### Stage of Disease



### Age of Respondents

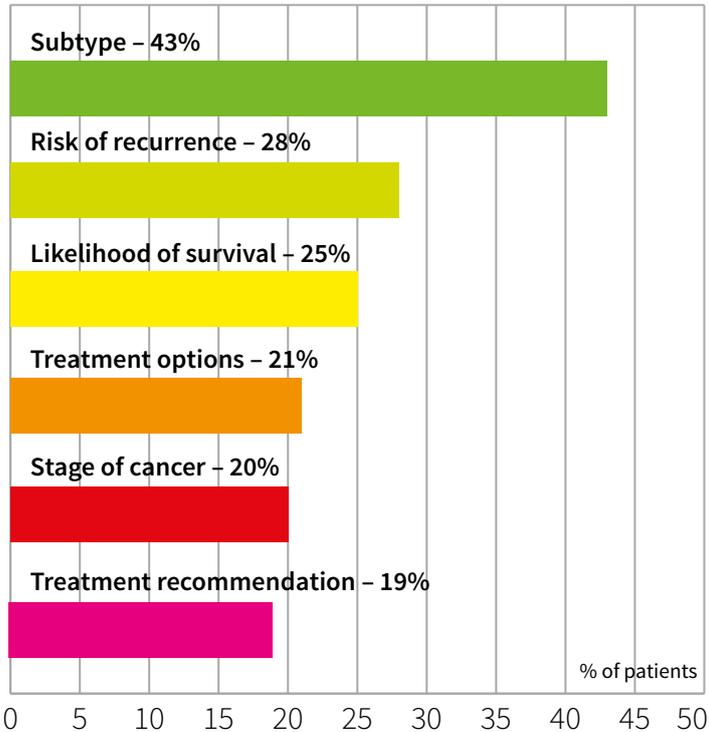


<sup>1</sup> Ferlay J, Soerjomataram I, Dikshit R, et al. Cancer incidence and mortality worldwide: sources, methods and major patterns in GLOBOCAN 2012. Int J Cancer 2015; 136(5): E359-86.

# We need to talk about: Knowledge and Understanding

Many patients around the world reported a lack of fundamental knowledge and understanding about their kidney cancer diagnosis.

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



Key elements of diagnosis such as the kidney cancer subtype, along with stage and grade, help determine which treatment options and long-term surveillance plans are recommended for an individual patient.

Yet the survey further revealed that **38%** of patients were not told their subtype at diagnosis.

At the time of the survey **11%** still didn't know their subtype.

It is critical that healthcare providers talk to patients and explain the details of their diagnosis. When patients have the facts and understand their options, they can be more engaged and participate more fully in their treatment. Knowledge can also help mitigate or manage psychosocial issues related to uncertainties about kidney cancer and long-term survivorship.



*“Overall patients in France consistently demonstrated the highest levels of knowledge and understanding related to their disease. While this is impressive, what we are most interested in is understanding their best practices and replicating them globally so patients worldwide can benefit.”*

*Dr Rachel Giles, IKCC Board Chair, The Netherlands*

# We need to talk about: **Quality of Life**

Kidney cancer has a profound effect on the lives of patients, carers, and families. There is considerable evidence to suggest that patients are choosing to 'suffer in silence' from the physical and psychosocial effects of their disease.

Despite the fact that the majority of patients are experiencing psychosocial issues related to their kidney cancer, 50% are not talking about them to any healthcare professional. Furthermore, the younger the patients are, the less likely they are to address them. However, of the patients who did speak to their doctor about psychosocial issues, 92% found those conversations helpful.

**We need to break the silence and start talking about the physical and psychological effects of kidney cancer. When patients and carers talk about concerns, fears, and impacts on daily living, they better understand what to expect, resources that may be available, and how side effects can be managed, which can lead to overall improved quality of life.**

## Gender Differences

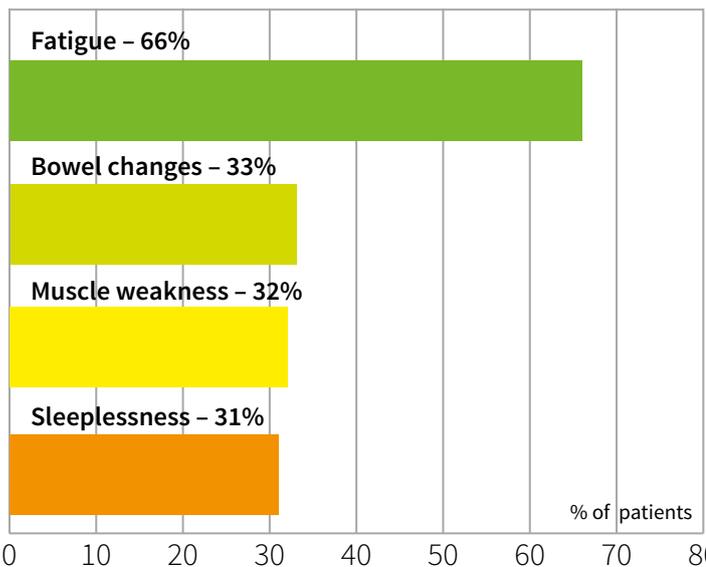
Along with differences in average time to diagnosis, men and women reported notable differences in the physical issues related to their kidney cancer. Males were more affected by changes in taste and smell, changes in sexual function, weight loss and skin reactions. Females were more affected by trouble concentrating, pain related to surgery and hair loss.

Across psychosocial issues, females were notably more affected by fear of recurrence than males. When reporting on their most difficult times, males were more likely to list side effects of treatment, whereas females ranked surgery and recovery along with waiting for surgery and scans as the most difficult.

## Physical Conditions

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

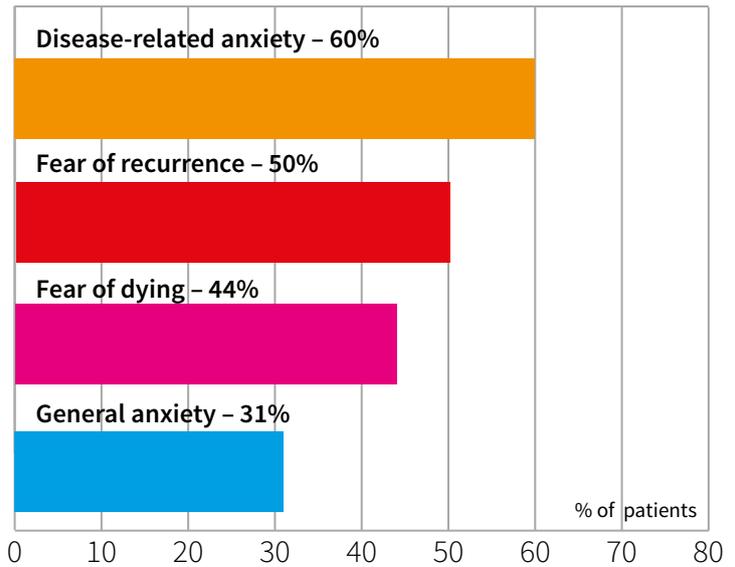
### Most common conditions included:



## Psychosocial Conditions

**96%** of patients said they were impacted by psychosocial issues.

### Most common conditions included:



\* The survey assessed 21 physical and 15 psychosocial conditions.

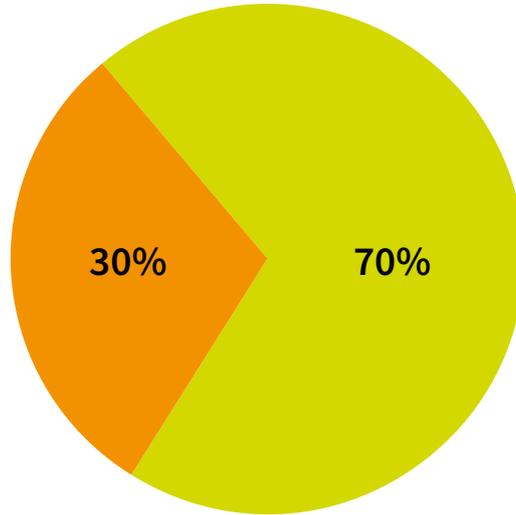
# We need to talk about: Clinical Trials

Clinical trials are the cornerstone of advancing treatment for kidney cancer. Every patient deserves access to the highest quality care and the opportunity to participate in research. As patient organisations, we believe research is the only way to improve outcomes and reduce the global burden of the disease.

However, the global patient survey showed that the majority of patients are not being asked to participate, despite their willingness to participate if asked.

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

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



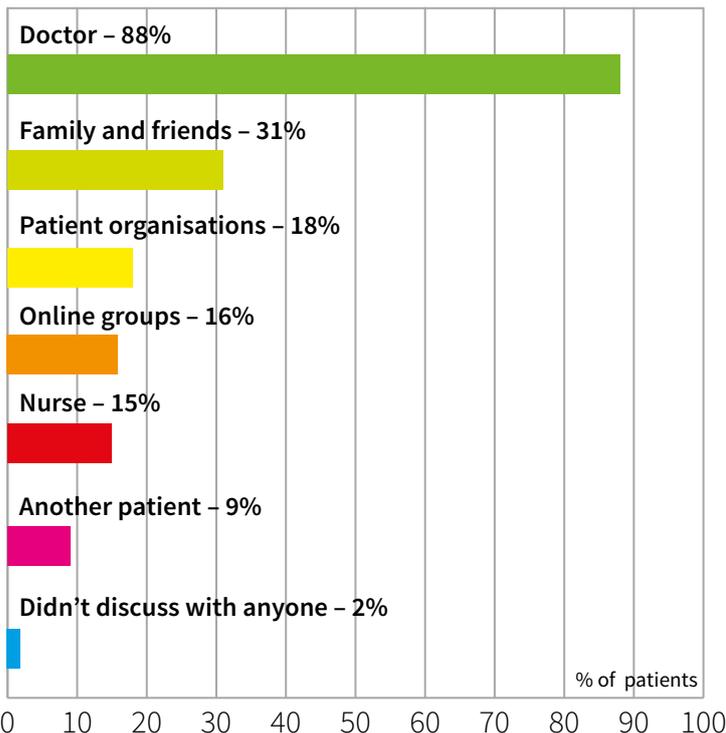
**70%** of patients had never been asked to participate in a clinical trial.

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.

## Discussing Clinical Trials

When patients are asked to participate in a clinical trial, overwhelmingly they want to talk about it. They need information about what participation entails, what the trials are studying or how it will affect their quality of life, but nonetheless, they are reaching out. The survey revealed patients discussed clinical trials with their:



**We need to talk about clinical trials – not only when we think a patient may potentially enroll in a specific study, but more broadly whenever there is an opportunity for them to help move our understanding of kidney cancer forward. Patient organisations around the world are key partners in providing credible and balanced information about clinical trials, and can ensure patients are getting the facts and making informed decisions about clinical trials and all other options.**



*"Patients who participate in clinical trials overwhelmingly report having a positive experience and receive excellent care and monitoring."*

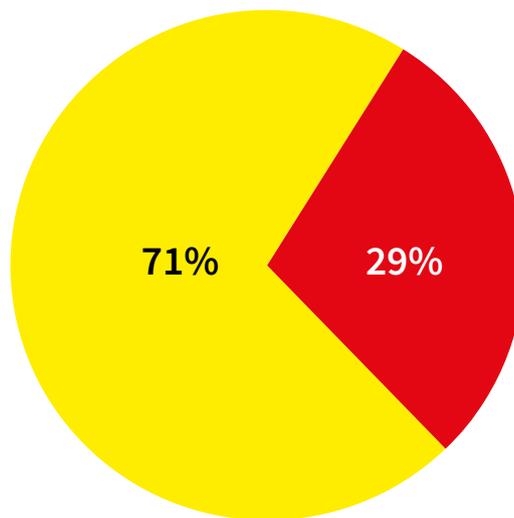
Deb Maskens, IKCC Vice-Chair

# We need to talk about: **Shared Decision Making**

Shared decision making is increasingly recognised as a pillar of patient-centred health care and is central to engaging patients in their own care. At the heart of shared decision making is a conversation – a conversation that brings together the clinician’s expertise, treatment options, evidence, risks and benefits, and the patient’s individual preferences, personal circumstances, goals, values and beliefs.

Despite the widespread acceptance of the value of shared decision making, the global patient survey showed that a surprisingly high number of patients were not involved at all in their treatment decisions.

**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 and  
– **30%** were stage 4.

**We need to talk about shared decision making. It literally starts with an open dialogue where patients and their care teams work in partnership to make the best possible decisions for each individual patient, according to the patient’s goals, expectations and values. To make this happen, patient organisations can continue to work alongside medical professionals to support patients in becoming more engaged in their own care.**



*“What we see in Canada is there is tremendous value when we as healthcare professionals initiate open communications with a patient about their treatment options. While we may be the subject matter experts, the individual’s values and preferences are equally important to incorporate into care decisions.”*

*Dr Daniel Heng, Tom Baker Cancer Centre, University of Calgary, Canada*

## Conclusions and Next Steps

The results of the first IKCC Global Patient Survey will be used in a variety of ways.

- First and foremost, the results will help identify priority programs and initiatives for IKCC globally and locally for Affiliate Organisations to inform their work.
- Several countries plan to use their national results as evidence to address gaps in kidney cancer care.
- Lastly, the results of this year's survey will be used as a benchmark by which to measure progress in coming years.

In addition to what is included in this document, the full Global Report is available at [www.IKCC.org](http://www.IKCC.org) where a more detailed account of the research can be viewed, including variations between:

- Country
- Gender
- Age category
- Stage of disease
- Subtypes (clear cell and rarer subtypes)

In addition, Country-Specific Reports are available where more than 100 people completed the survey for: Canada, Germany, France, India, Japan, Mexico, South Korea, the United Kingdom and the United States.

## Acknowledgements

The IKCC would like to acknowledge all of the people and organisations who contributed to the development and success of the inaugural Global Patient Survey: Mapping the Kidney Cancer Patient Experience Worldwide.

Thank you to all the IKCC Affiliate Organisations around the world who supported the Global Patient Survey, from concept to implementation. Your help in developing the survey, adapting it to local regions and promoting the survey to patients and carers in your community was invaluable.

This project has been funded with sponsorship from the following companies in full compliance with the Code of Conduct of the International Kidney Cancer Coalition:



### Project Steering Committee Members:

Robert Bick, Kidney Cancer Canada  
Malcolm Packer, Kidney Cancer UK  
Robin Martinez, SmartPatients USA  
Deborah Maskens, International Kidney Cancer Coalition

**The IKCC is also very grateful to all the patients and carers who took the time to complete the survey and share their experiences and insights, which will inform the work of our organisations worldwide.**



## About IKCC

The International Kidney Cancer Coalition (IKCC) is an independent international network of patient organisations that focus exclusively, or include a specific focus, on kidney cancer. The organisation was born from a very strong desire among various national kidney cancer patient groups to network, cooperate and share materials, knowledge, and experiences.

Kidney cancer is a global issue. Every year, 338,000 people worldwide will be diagnosed with kidney cancer. Research and clinical trials in kidney cancer take place across continents and many kidney cancer experts sit on international panels. By working together and collecting the experiences of many patients in different countries, we represent the perspectives, insights and experiences of kidney cancer patients around the world and empower the kidney cancer community through advocacy, awareness, information and research.

### **About the Global Patient Survey: Mapping the Kidney Cancer Patient Experience Worldwide**

IKCC'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.

From September to October 2018, the survey was conducted online and in paper form in 14 languages in 43 countries. It was completed by kidney cancer patients and carers identified by IKCC's Affiliate Organisations and through social media in multiple languages. The survey was developed and data was independently analysed by Perception Insight, a Canadian firm specialising in global market research.

**For more information and the complete  
Global Patient Survey Reports, visit:  
[www.IKCC.org/global-patient-survey](http://www.IKCC.org/global-patient-survey).**

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