

# Global Patient Survey 2020: Mapping the Kidney Cancer Patient Experience Worldwide

## Highlights Report



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

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

We're pleased to share the second edition of the *Mapping the Kidney Cancer Patient Experience Worldwide Highlights Report*, based on the results of the IKCC Global Patient Survey 2020.

In 2018, IKCC Affiliate Organisations came together to recognise and address an evidence gap in research about the kidney cancer patient experience worldwide. We measured the real-world experiences of patients and caregivers related to kidney cancer diagnosis, knowledge, quality of life and clinical trials.

The survey results provided evidence-based guidance to our work to improve kidney cancer patients' lives. They were also presented at national and international meetings and conferences and shared broadly with stakeholders.

The Global Patient Survey 2020 explores many of the same areas as the first survey, but also examines some areas more deeply and considers how they are interconnected in patients' experiences and outcomes. We again asked patients about their knowledge and understanding of their diagnosis and treatment, but also explored their thoughts regarding biopsies. We assessed individuals' quality of life, but also the role physical activity plays. We also partnered with the Università Cattolica del Sacro Cuore in Italy to incorporate the Patient Health Engagement Scale, which assessed patients' state as it relates to living with kidney cancer.

We are very excited to report this year's survey included more respondents than the inaugural year, with over 2,000 patients and caregivers from 41 countries sharing their experiences and insights. As well, the results of the survey demonstrate a consolidated baseline of information with which IKCC and Affiliate Organisations can plan and execute initiatives confidently knowing they address the needs of the community.

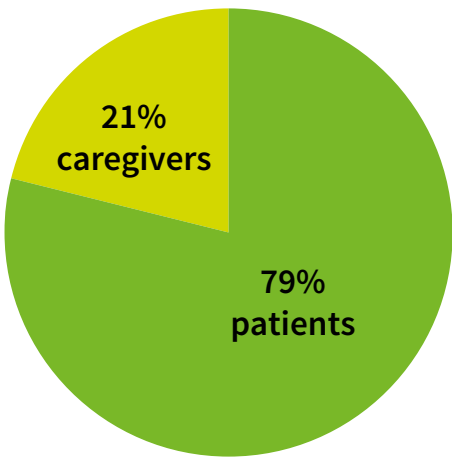
We invite you to explore the highlights of IKCC's Global Patient Survey 2020 in this report and join the conversation about how we can improve the lives of patients and reduce the burden of kidney cancer worldwide. It all starts with talking about kidney cancer.

*The Global Patient Survey 2020 Steering Committee*

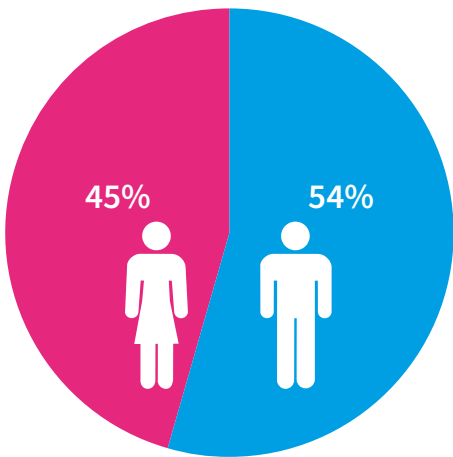
# Demographics

The survey included **2,012** respondents in **41** countries.

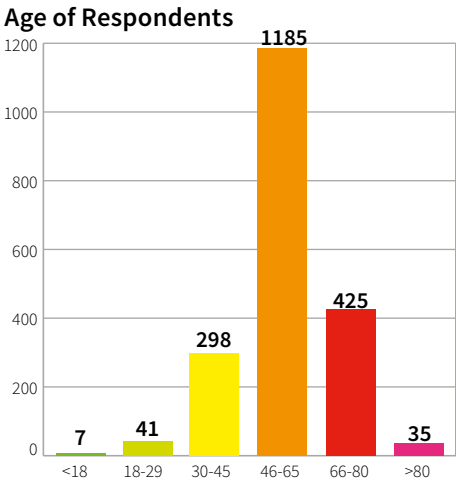
The Global Patient Survey 2020 included respondents from the United States (16%), South Korea (15%), Canada (12%), France (12%), India (8%), the United Kingdom (7%), Japan (8%), Spain (3%), Australia (2%), Germany (2%), Brazil (1%), Italy (1%), The Netherlands (1%), Sweden (1%), other (5%).



Compared to the first survey, more patients responded, compared to caregivers.



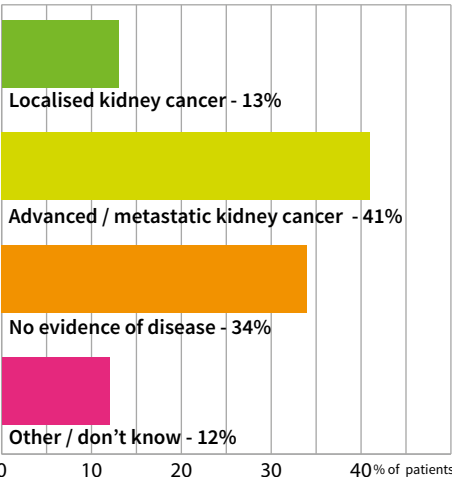
1% of respondents did not identify as either man or woman



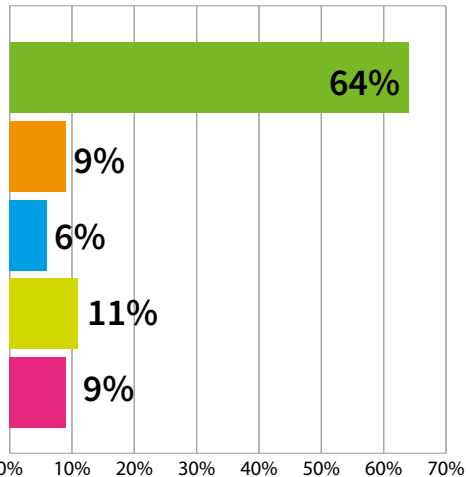
The age distribution of the 2020 survey is similar to that of the 2018 survey.

## About the Respondents’ Diagnosis

Stage of Disease



Subtype



Clear cell renal cell carcinoma – 64%  
Papillary renal cell carcinoma – 9%  
Chromophobe renal cell carcinoma – 6%  
Other – 11%  
Don't know / was not told – 9%

See the full list of respondents’ subtypes in the complete Global Patient Survey Report.

“Participating in the Global Patient Survey has allowed me, along with thousands of other patients around the world, to have our real-life experiences heard, counted and considered to improve the lives of people with kidney cancer. That is the very definition of patient-centred healthcare.”

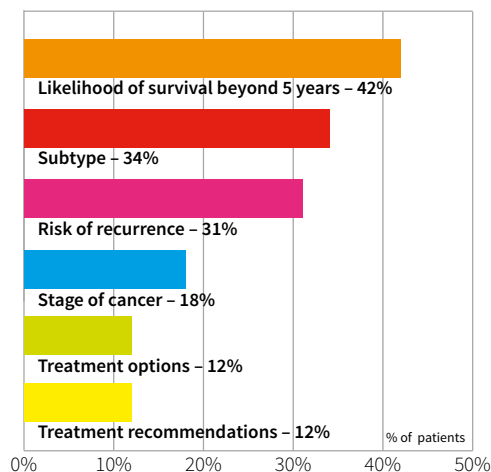
Subbegowda Tammegowda,  
V Care Foundation, India.



## We need to talk about: Knowledge and Understanding

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

**At the time of diagnosis, the following were **not** explained to patients in a way they could understand:**



While there are some small differences between the data in 2018 and 2020, the trend is the same – too many patients are not being given the full picture of their disease at diagnosis. Information about kidney cancer subtype and stage help determine the best approach to treatment and surveillance and also help give patients the option to participate in the decision-making process in an informed way.

Furthermore, when patients don't understand their risk of recurrence or the likelihood of survival, it can have significant psychosocial effects and result in increased fear of recurrence, general and disease-related anxiety, and a fear of dying.

### Subtype and Younger-Onset Kidney Cancer

When someone is diagnosed with younger-onset kidney cancer (under age 46) there is an increased probability of hereditary syndromes (such as VHL). However, according to the survey, only 50% of people under 29 and 53% between 30 and 45 were told their kidney cancer subtype at diagnosis, which can, in some cases, help the diagnosis of a hereditary syndrome.

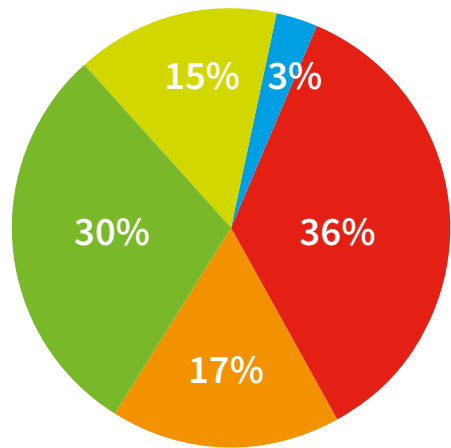
This could point to inadequate screening for germline mutations and this group not being considered at a higher risk for additional tumours, either within the kidney or at other locations. In addition, a family history should be taken for younger patients.

# New in 2020: Talking about biopsies

In 2020, the Global Patient Survey asked individuals about their experiences and thoughts related to biopsies.

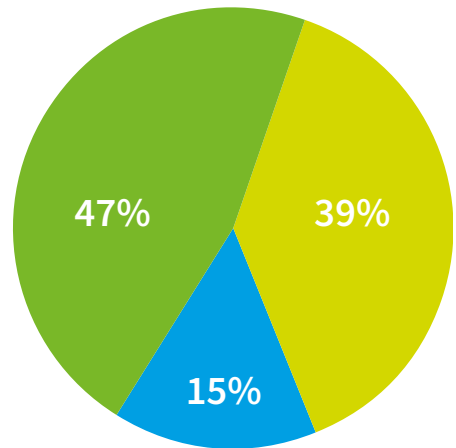
Biopsies are the removal of cells or tissues using a thin needle that are then examined by a pathologist to determine if they are cancerous or not. Related to kidney cancer, biopsies can identify if the mass in question is benign and does not need to be treated, help identify biomarkers to determine the best targeted treatment or if a clinical trial is available, and in the case of metastatic kidney cancer, determine if tumours are related to the original cancer site.

Have you been offered a biopsy?



Yes, of the kidney growth – 30%  
Yes, another part of my body – 15%  
Yes, but I chose not to – 3%  
No, the tissue was examined after it was removed by surgery – 36%  
No, I was not offered a biopsy – 17%

Would you be willing to have a biopsy in the future?



Yes – 47%  
Maybe – 39%  
No – 15%

There is a hypothesis in the medical community that patients do not want biopsies, but the refusal rate of only **3%** tells us this is not true. It is further confirmed that only **15%** would refuse a biopsy in the future.

There is an opportunity to offer biopsies more consistently to better understand the individual’s mass, as well as include them in the findings and treatment planning.



*“Improvements in diagnostics and better clinical knowledge have improved both understanding and treatment of kidney cancers. However, as healthcare providers, we need to consistently talk to patients about the details of their diagnosis. This will help them make informed decisions about their own care, and can also help reduce psychosocial issues associated with uncertainties and survivorship.”*

Dr Michael Jewett, Princess Margaret Cancer Center, University of Toronto, Canada

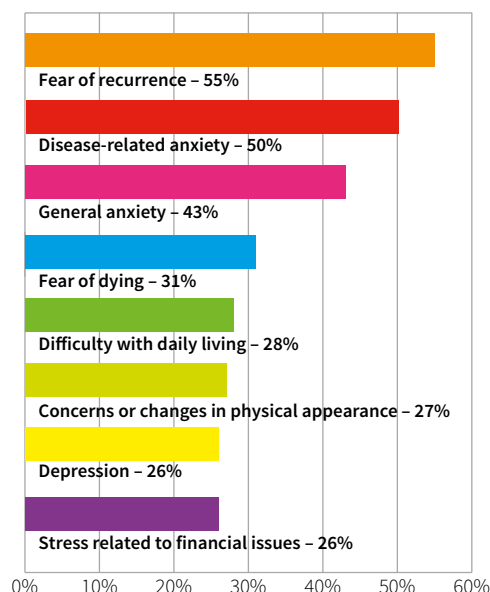


## We need to talk about: Quality of Life

In addition to the physical effects of kidney cancer and treatment, **96%** of patients are also living with many associated psychosocial issues that cannot be as easily seen by the people around them.

### Psychosocial Conditions

Most common psychosocial issues included:



While this survey ran during the global COVID-19 pandemic and may have influenced responses, the general trend of significant psychosocial impact on patients is comparable to the findings in 2018.

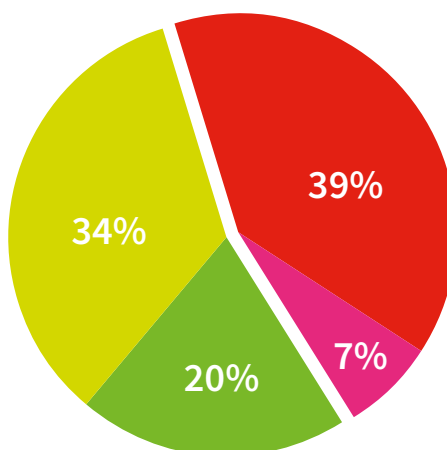
Similar to 2018, half of patients (**50%**) are not talking about their psychosocial issues with their physician or health team. However, **60%** indicated they found patient support groups helpful in addressing their issues.

## New in 2020: Talking about physical activity

In 2020, the Global Patient Survey asked individuals about their current level of physical activity.

Exercise can help prevent kidney cancer and help people living with it lessen the impact of treatment on their physical and mental health, regardless of stage. To achieve optimal benefits, experts recommend approximately **30 minutes** of aerobic and resistance training three times per week. However, some physical activity is better than none.

### Current Level of Physical Activity (minutes of physical activity / week)

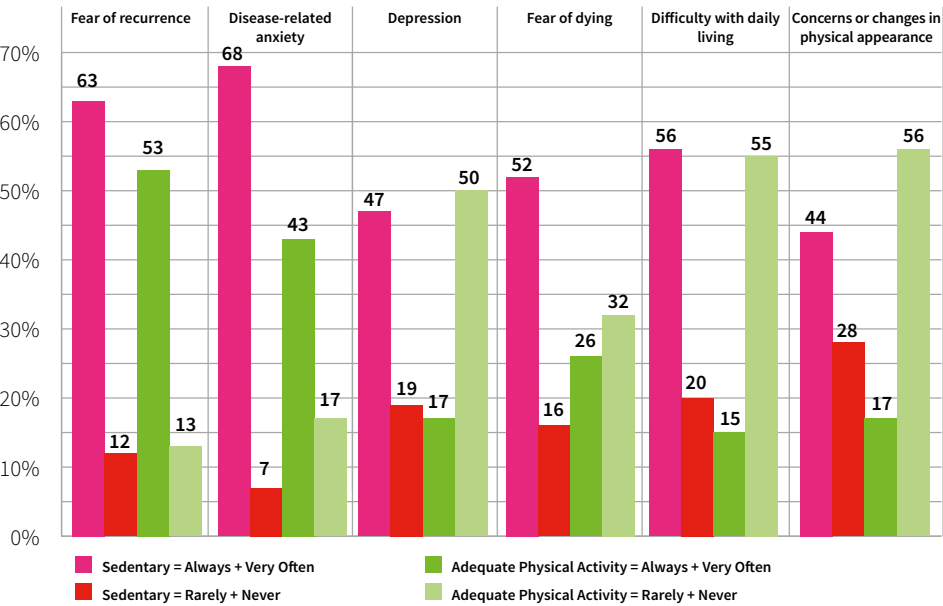


Nearly half (**46%**) of respondents self-reported they are not meeting the recommended guidelines for physical activity. This significant lack of physical activity was seen in all age groups.

Completely sedentary (0) – 7%  
Insufficiently active (1 – 149) – 39%

Sufficiently active (150 – 299) – 34%  
Above guidelines for physical activity (300+) – 20%

Regular and sustained physical activity is known to help people manage and reduce the mental burden related to cancer and treatment. The survey examined the relationship between respondents’ physical activity level and the frequency of psychosocial issues. While physical activity doesn’t eliminate psychosocial issues, most of the time their frequency is significantly reduced.



We need to talk about physical activity. Making regular exercise a part of an individual’s treatment plan from the outset is a safe and effective way to help manage treatment side-effects and the accompanying psychosocial impacts of cancer. It also offers people a positive way for individuals to be proactive about and engaged in their health.



*“Regardless of your stage of cancer, find activities that you enjoy to get moving, such as walking. We know when people move as much as they can tolerate, they feel better physically and mentally.”*

*Dr Linda Trinh, Assistant Professor, Exercise and Cancer Survivorship at the University of Toronto, Canada*

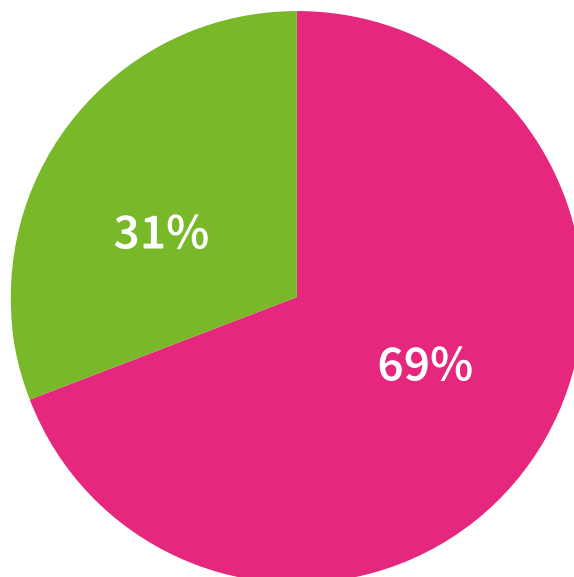
## We need to talk about: **Clinical Trials**

All the advances seen in patient outcomes in kidney cancer can be linked back to clinical trials. From new therapies to treat metastatic disease to improving surgical and surveillance techniques of localised disease, new ideas are tested, and when proven, move into standard of care.

Similar to the findings in 2018, the global patient survey showed the majority of patients are not being asked to participate in clinical trials, despite their willingness to participate if asked.

**31%** of patients were asked to participate in a clinical trial.

Of those asked, **62%** agreed and the majority were satisfied with their experience.



**69%** of patients had never been asked to participate in a clinical trial.

This includes **2%** who indicated their country didn't have any clinical trials.

Of those, **65%** said it was likely they would have participated if they had been asked.

There is a small decrease in clinical trial participation compared to 2018. This may be related to the effect of the COVID-19 pandemic on clinical research.

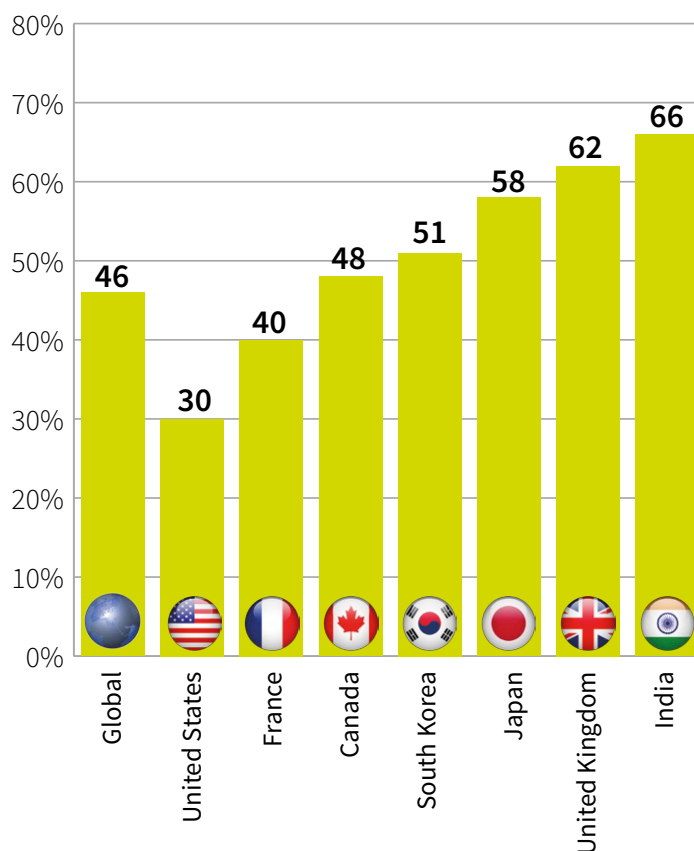
### **According to the survey, the most common reasons to participate in a clinical trial include:**

- ✓ My doctor recommended it
- ✓ I thought it might offer better care
- ✓ I wanted a chance to support cancer research



The survey also found that **46%** of respondents reported no one had discussed clinical trials with them. There was a significant range in this number from country to country. This variance may be attributed to where clinical trials are available.

#### No one discussed clinical trials with me:



*“We know a huge barrier to accessing clinical trials is that too often they aren’t where patients live. More sites, in more cities and more countries globally, would greatly open the pool for improved research, but also give more patients access to new treatments and regimes.”*

*Dr Eric Jonasch, University of Texas MD Anderson Cancer Centre, Houston, USA*

**We need to talk about clinical trials – regardless of if there is a local trial available or we think the individual is interested in participating in research.**

**Talking about clinical trials is an important step in engaging patients, learning more about the process of advancing healthcare and encouraging them to be active partners in their own care.**

# New in 2020 – We need to talk about: Patient Engagement

The Global Patient Survey 2020 added a new aspect to help measure patients' engagement in their own care. The Patient Health Engagement Scale (PHE-S) is a validated instrument developed by Università Cattolica del Sacro Cuore in Italy and was incorporated into the survey. The PHE-S defines how a patient's engagement in their own health relates to how they have processed and accepted the disease, categorised into four states.

## The Patient Health Engagement Model



### **Eudaimonic project** **"I am a person"**

These patients are balanced, they appear to:

- have fully accepted their health condition
- be able to play an active role in their health (and in the health of others)

Their focus is on being a person as a whole i.e. with their connections to many aspects of daily life, not just their role as a patient.



### **Adhesion** **"I am a patient"**

These patients have accepted their condition, BUT they are still unable to navigate unexpected events related to their illness or healthcare. They can easily revert to arousal or blackout stages. Their focus is on being a patient.



### **Arousal** **"I am a sick body"**

These patients have acquired a first knowledge about their health condition and they are learning to cope with it. They are generally hypervigilant, anxious, over-reactive. Their focus is on being a sick body.

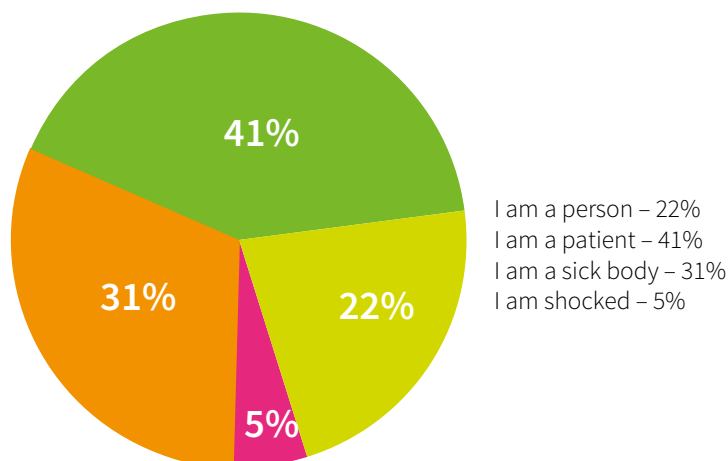


### **Blackout** **"I am shocked"**

These patients feel overwhelmed and shocked. They are emotionally fragile and appear passive/withdrawn. They prefer to rely on others for significant decisions and action about their healthcare.

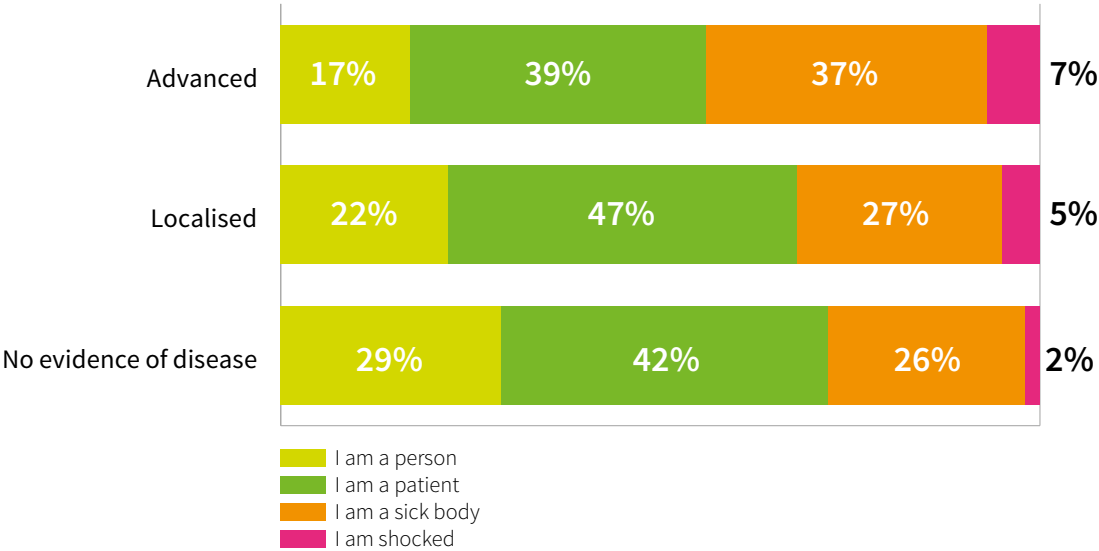
*EngageMinds Hub Research Center, Università Cattolica del Sacro Cuore, Milan, Italy*

## PHE-S: Kidney Cancer Patient State



It was also revealed that an individual's stage of disease may affect their state. People with advanced disease were more likely to report a less empowered state, while those with no evidence of disease, a more positive state.

PHE-S: Kidney Cancer Patient State by Stage



*“When people are more engaged in their care and treatment, they experience better quality of life and improved quantity of life. Taking the time and making the effort to inform, educate and consider patients’ values will lead to improved outcomes overall.”*

*Dr Serena Barello, Assistant Professor of Consumer & Health Psychology, EngageMinds Hub Research Center, Università Cattolica del Sacro Cuore, Milan Italy*

Shared Decision Making

1 in 7 respondents said they were not as involved as they wanted to be in decisions about their treatment.

Furthermore, another 1/3 said they were only involved to some extent.

Despite that shared decision making is globally accepted as a central pillar to patient engagement, there is still more work to be done to ensure patients' values are incorporated into their treatment and care planning.

# Conclusion

When we talk about kidney cancer, it is important to look beyond the clinical disease. We need to consider what information and knowledge patients need and want *and* how they want to receive it. We need to think about what information is needed beyond medical treatment, from clinical research to incorporating physical activity into their lives. And we need to consider beyond the individual's physical health and include the effects of kidney cancer on their mental wellness.

Additional research is needed to continue to explore the interconnectivity between all aspects of the patient experience and how it affects the person as a whole. Because when a patient is engaged it ultimately improves their overall health.

## **An Evidence-Based Approach to Reducing the Burden of Kidney Cancer**

The results of the second 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. The results of the survey will be used to identify trends and measure progress toward our goal of reducing the global burden of kidney cancer.

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
- Stage of disease
- Age category
- Level of physical activity

Country-Specific Reports are also available when more than 100 people completed the survey for: Canada, France, India, Japan, South Korea, the United Kingdom and the United States.

# Acknowledgements

IKCC thanks all the organisations and individuals who contributed to the development and success of the Global Patient Survey 2020: Mapping the Kidney Cancer Patient Experience Worldwide.

Special thanks to the members of the Project Steering Committee (listed below) who designed and tested the survey, and to Picker Institute Europe (especially Hanan L'Estrange-Snowden) for execution and analysis of the survey.

Sincere appreciation to all the global network of Affiliate Organisations who continue to support the Global Patient Survey. Your help in creating the survey, adapting it to local regions and promoting the survey to patients and carers in your community is invaluable.

IKCC is also very grateful to all the patients and carers who shared their experiences with kidney cancer and took the time to complete the survey. These insights will continue to inform the work of our organisations worldwide.

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 (Canada)  
Carlos Castro, Asociación Ale (Mexico)  
Rachel Giles, International Kidney Cancer Coalition, (Netherlands)  
Karin Kastrati, Das Lebenshaus, (Germany)  
Sara MacLennan, University of Aberdeen (United Kingdom)  
Robin Martinez, Smart Patients Inc (United States)  
Deb Maskens, Kidney Cancer Canada (Canada)  
Juan Carlo Julián Mauro JC, Federación Nacional de Asociaciones ALCER (Spain)  
Malcolm Packer, Kidney Cancer UK (United Kingdom)



## About IKCC

The International Kidney Cancer Coalition (IKCC) is an independent international network of over 45 patient organisations that focus exclusively, or include a specific focus, on kidney cancer. Based in Amsterdam, the Netherlands, 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 around the world.

Kidney cancer is a global issue. Every year, an estimated 431,000 people worldwide will be diagnosed with kidney cancer.<sup>1)</sup> 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.

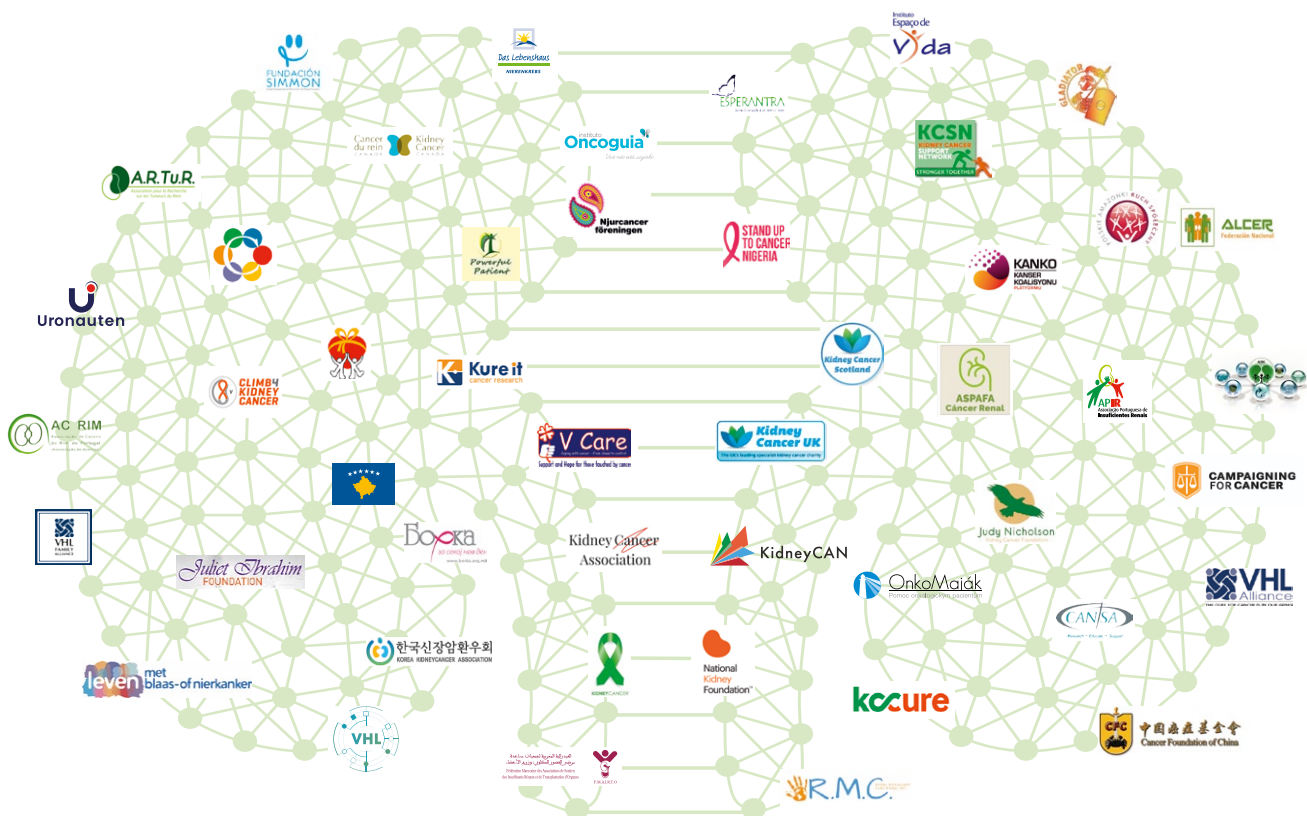
From October 2020 to January 2021, the survey was conducted in 13 languages in 41 countries. It was completed by kidney cancer patients and carers identified by IKCC's Affiliate Organisations and through social media in multiple languages. The survey was developed and data were independently analysed by Picker, a UK-based health and social care charity which carries out research to understand individuals' needs and experiences of care.

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

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

1) [https://gco.iarc.fr/today/online-analysis-table?v=2020&mode=cancer&mode\\_population=continents&population=900&populations=900&key=asr&sex=0&cancer=39&type=0&statistic=5&prevalence=0&populationgroup=0&ages\\_group%5B%5D=0&agesgroup%5B%5D=17&group\\_cancer=1&include\\_nmsc=1&include\\_nmsc\\_other=1](https://gco.iarc.fr/today/online-analysis-table?v=2020&mode=cancer&mode_population=continents&population=900&populations=900&key=asr&sex=0&cancer=39&type=0&statistic=5&prevalence=0&populationgroup=0&ages_group%5B%5D=0&agesgroup%5B%5D=17&group_cancer=1&include_nmsc=1&include_nmsc_other=1)







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### **International Kidney Cancer Coalition**

Registered Office:  
't Ven 30  
1115HB Duivendrecht,  
The Netherlands  
Email: [info@ikcc.org](mailto:info@ikcc.org)



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