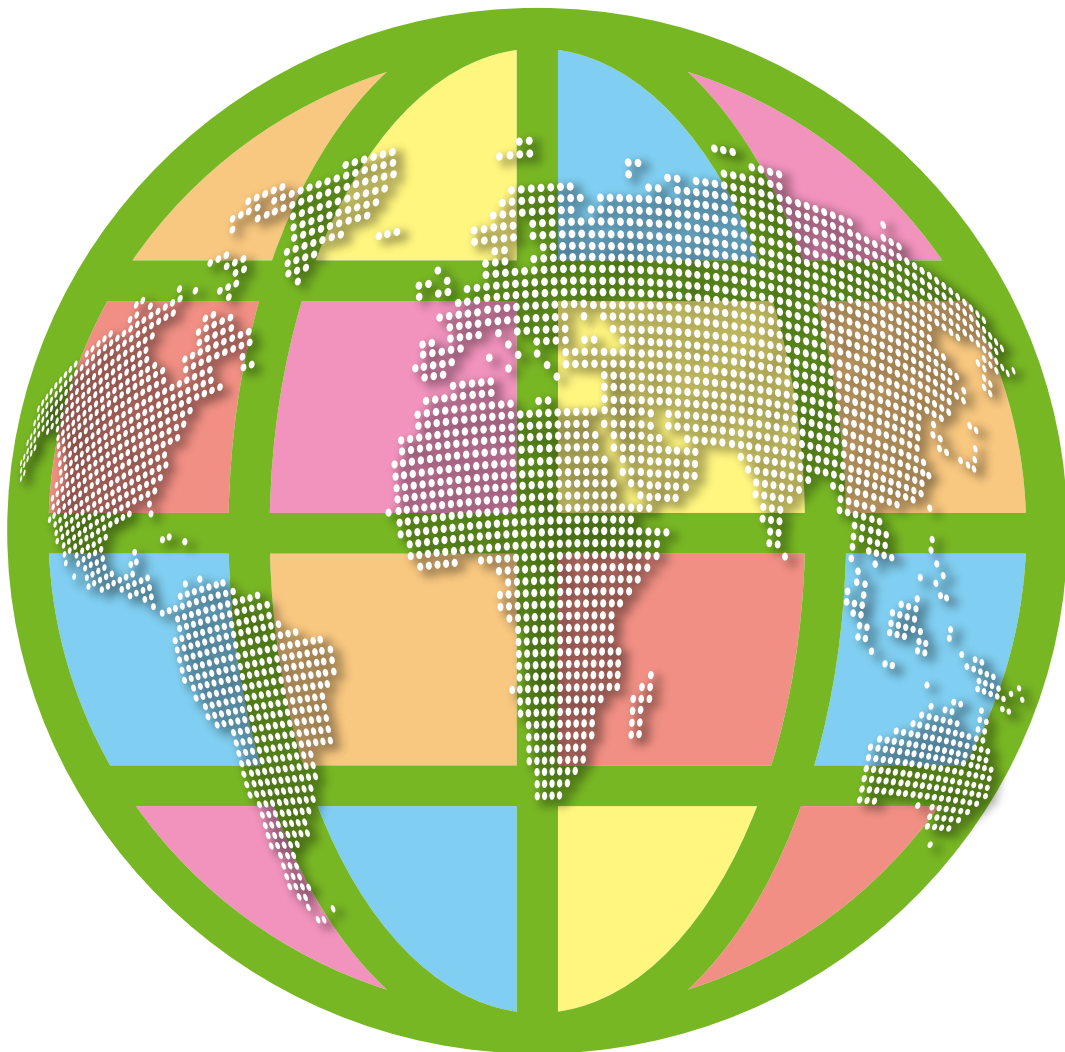


Global Patient Survey 2022: Mapping the Kidney Cancer Patient Experience Worldwide

Highlights Report



Generating evidence to improve the lives
of people living with kidney cancer.

A Message from the 2022 Global Patient Survey Steering Committee

Welcome to the third edition of the *Mapping the Kidney Cancer Patient Experience Worldwide Highlights Report*, based on the results of the IKCC 2022 Global Patient Survey.

In 2018, IKCC Affiliate Organisations first came together to address an evidence gap in the kidney cancer patient experience worldwide. Since then, the biennial survey measures the real-world experiences of patients and caregivers related to kidney cancer diagnosis, knowledge, quality of life and clinical trials and helps identify how the patient experience is changing over time.

Generating this evidence is foundational to improving the lives of people living with kidney cancer. IKCC and local patient organisations can accurately represent patients' perspectives, insights and needs and help empower the kidney cancer community through advocacy, awareness, information and research.

The 2022 Global Patient Survey builds on many of the same areas as the previous surveys, and also explores some new areas. In 2022, we again asked patients about their knowledge and understanding of their diagnosis and treatment, and also explored their thoughts regarding second opinions. We assessed individuals' quality of life and also their understanding of the role supportive care can play. We also focused some questions on patients' experience with genetic testing.

We're excited to report interest in the Global Patient Survey continues to grow. The 2022 survey saw a 10% increase in participation. We are grateful to the patients, carers and survivors from around the world who took the time to share their experiences and insights.

Within these pages you will find the overall highlights of the survey and evidence that more awareness, education, and advocacy is needed to improve the lives of people with kidney cancer. We hope you will join us.

The 2022 Global Patient Survey Steering Committee

Project Steering Committee Members:

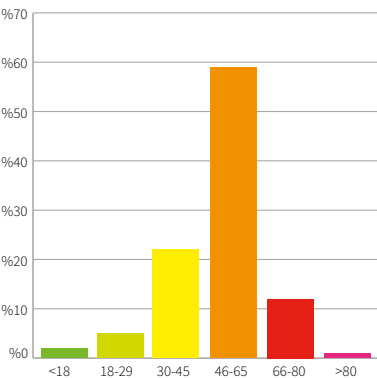
Robert Bick, Kidney Cancer Canada (Canada)
Carlos Castro, Asociación Ale (Mexico)
Rachel Giles, International Kidney Cancer Coalition (The Netherlands)
Karin Kastrati, Nierenkrebs-Netzwerk Deutschland (Germany)
Sara MacLennan, University of Aberdeen (United Kingdom)
Robin Martinez, Smart Patients Inc (United States)
Deb Maskens, Kidney Cancer Canada (Canada)
Juan Carlo Julián Mauro JC, Federación Nacional ALCER (Spain)

About the Survey Respondents

The 2022 Global Patient Survey had **2,213** respondents from **39** countries.

Top responding countries included France (11%), Republic of Korea (9%), the United Kingdom (7%), Canada (6%), Germany (6%), Japan (5%), the United States (5%), India (5%), Mexico (5%), and South Africa (4%).

Age of Respondents

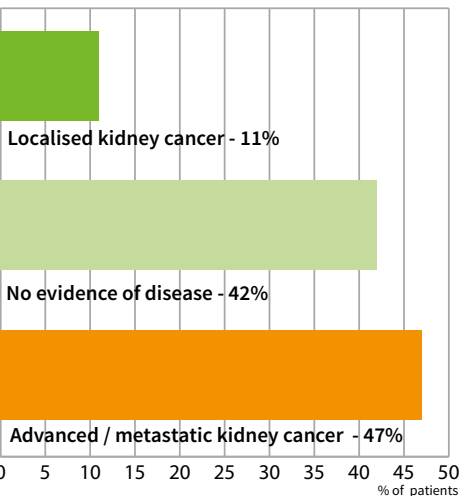


The age distribution of the 2022 survey is similar to past surveys and reflects diagnosis in the general population.¹

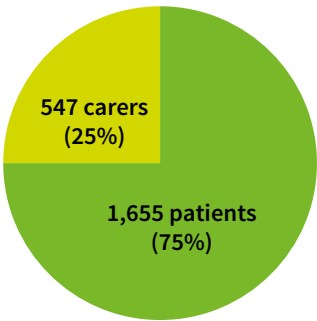
1) Shuch B, et al. J Clin Oncol. 2014 Feb 10;32(5):431-7

About the Respondents' Diagnosis

Stage of Disease

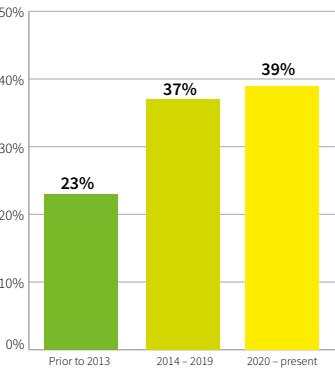


Most people who reported no evidence of disease (NED) were most likely diagnosed with localised disease and their cancer was treated surgically. Respondents who indicated NED and localised kidney cancer were analysed as a single group.



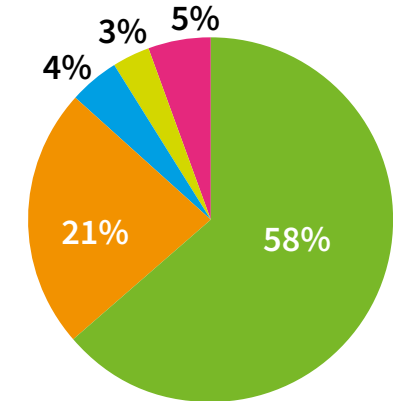
The number of respondents has increased with each survey.

Year of Diagnosis



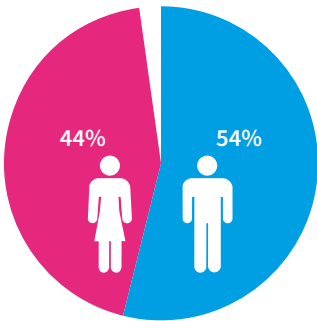
Approximately 2 in 5 patients were diagnosed since the beginning of the Covid-19 pandemic, which affected treatment and care options.

Subtype



Clear cell renal cell carcinoma – 58%
Papillary renal cell carcinoma – 21%
Chromophobe renal cell carcinoma – 4%
Other – 3%
Don't know / was not told – 5%

When compared to the 2020 Global Patient Survey, more people could identify their subtype.



1% of respondents did not wish to identify and 1% preferred to self-describe.

“We encourage participation in the Global Patient Survey on kidney cancer because it not only contributes to the global patient-driven evidence about living with the disease, but it also gives us the opportunity to better understand the experiences of people in Germany and tailor our offerings to meet the needs of our community.”

Daniel Tigges,
Association for VHL Affected Families, Germany



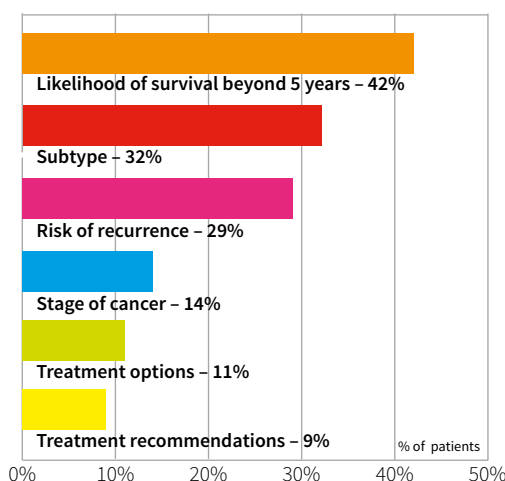
Knowledge and Understanding

At diagnosis, too many patients around the world continue to report a lack of understanding about the details of their diagnosis. The Global Patient Surveys in 2018 and 2020 had similar findings.

The need for more consistent and understandable information at diagnosis continues to be needed to improve patients' experiences. When people know and understand more about their diagnosis, they are better 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:**



Stage Matters

People with localised or advanced kidney cancer diagnoses face different approaches to treatment and different prognoses. This may help account for the notable differences between people diagnosed at a localised stage compared to an advanced stage of kidney cancer.

More people diagnosed at a localised stage reported receiving a complete understanding of their treatment options (**58%**) and treatment recommendations (**58%**), compared with those with advanced disease (**50%** and **53%** respectively).

However, more people with advanced disease had a complete understanding of the likelihood of surviving cancer beyond 5 years (**47%**) compared with those with localised disease (**37%**).

The evidence shows that regardless of stage, all patients need the best possible information, but that information must be tailored to their situation and personal needs. The complexity of the diagnosis and treatments must be considered alongside the level of detail and involvement the patient chooses.



“Complete knowledge and understanding at the time of diagnosis is the foundation upon which strong patient engagement is built. We have a responsibility as members of the care team to not only provide information to patients, but do it in a way that is understandable and meaningful because it helps people understand their situation and navigate their way forward.”

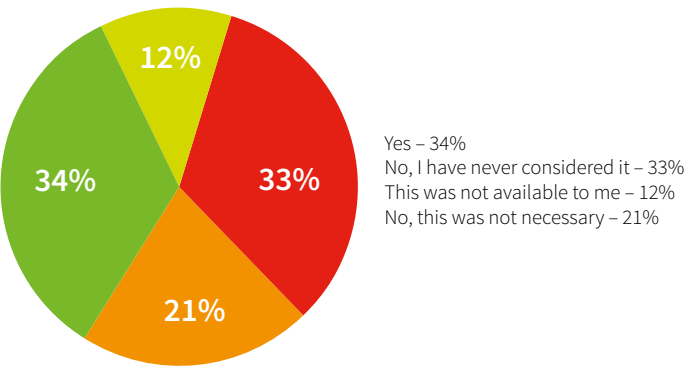
Prof. Axel Bex, Royal Free Hospital United Kingdom, and Netherlands Cancer Institute, The Netherlands

New in 2022: Second Opinions

When facing a life-altering diagnosis like kidney cancer, getting a second opinion from another healthcare professional can offer more information, access to different expertise and build more confidence in making healthcare decisions.

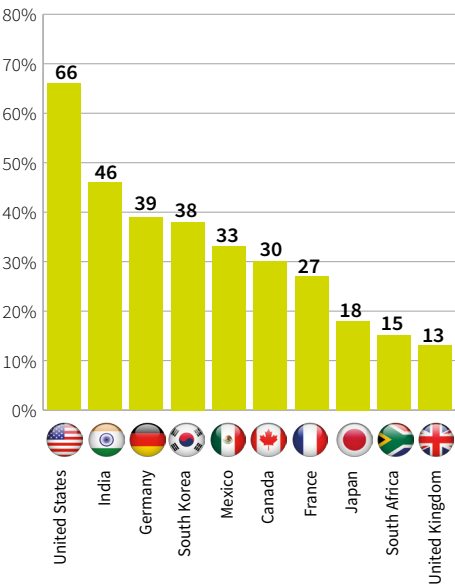
The 2022 Global Patient Survey revealed that globally, only **one-third** of people sought a second opinion, with an equal number of people reporting they didn't consider it and 12% citing it not available to them.

Did you seek a second opinion? (Global)

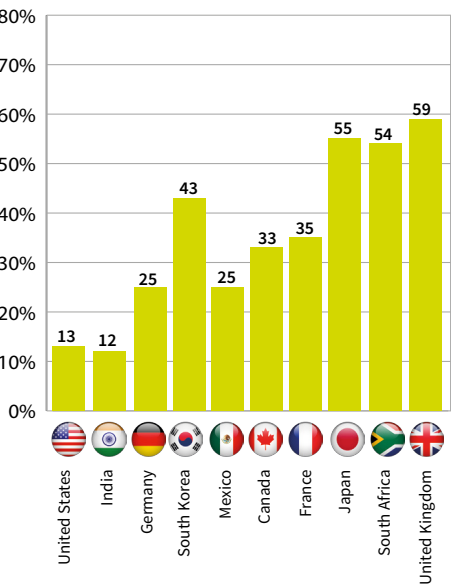


However, when the results are viewed by country, there are significant variations.

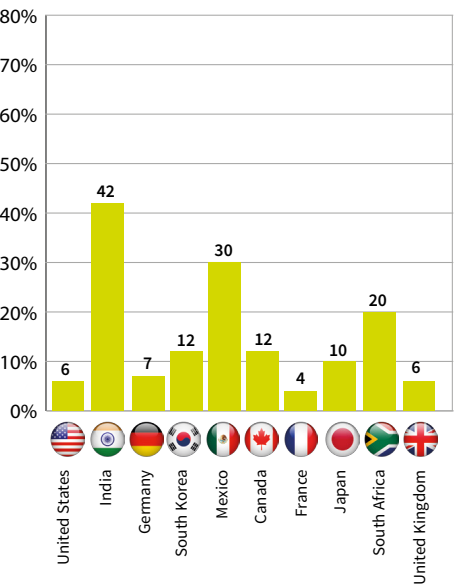
Sought a second opinion:



Did not consider a second opinion:



Second opinion was not available:



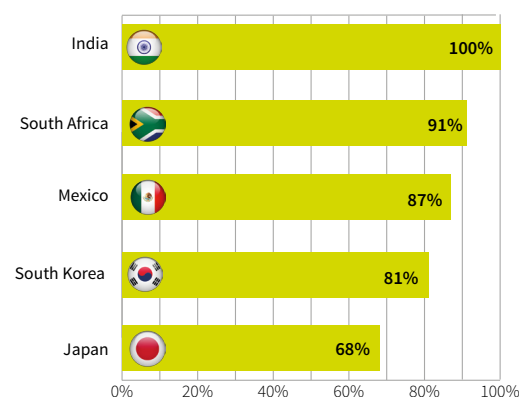
The variations seen in choosing and accessing second opinions at kidney cancer diagnosis could be attributed to differences in culture and healthcare systems. As a result, patients currently have inequitable access to second opinions, which can be important in helping patients making decisions and feeling empowered within their treatment.

Kidney Cancer Treatment

Treatment is critical to anyone diagnosed with kidney cancer. As such, it is imperative to minimize the barriers patients face when accessing treatment.

Globally, **46%** of patients said they did not face any barriers to treatment. However, when responses are examined by country, patients in a small number of countries carry the majority of barriers.

% of patients facing barriers to treatment

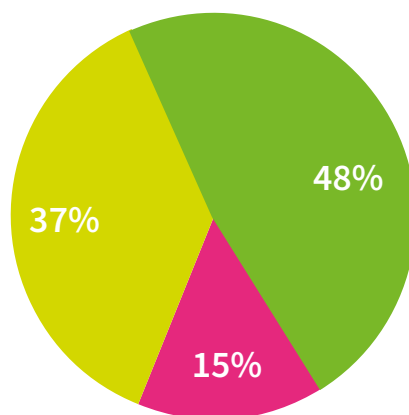


The most common barriers experienced include cost of treatment, wait-time to treatment, language, and prohibitive travel.

Shared Decision-Making

Despite that shared decision-making is accepted as an important pillar of patient engagement, the 2022 survey reported little change in patients' involvement in their treatment plans. While nearly half (**48%**) of people were definitely as involved as they wanted to be, more than one-third (**38%**) answered to some extent and **15%** said no. These data underscore that little has changed in shared decision-making practices since 2018.

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%

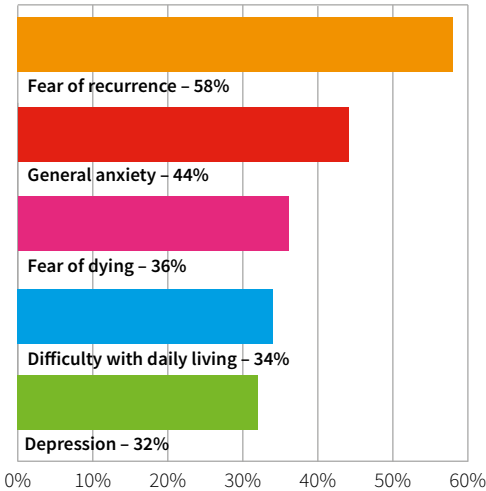
Shared decision-making goes beyond the patient and healthcare professionals. Five out of 6 respondents said they had help making treatment decisions citing many different people including their partner or spouse, their children, other family members, friends, patient organisations and online resources. Only **17%** of people said they made decisions alone.

Quality of Life

The 2022 Global Patient Survey found that the majority of respondents continue to report they are experiencing psychosocial issues as a result of living with kidney cancer, with little change from previous surveys.

The evidence shows we need more open dialogue about concerns, fears, and impacts on daily living so people can better understand what to expect and learn about available resources. This can lead to overall improved quality of life. It is equally important for physicians and allied healthcare teams to consider patients' psychological health, evaluate it and prioritize its treatment.

Most common psychosocial issues included:

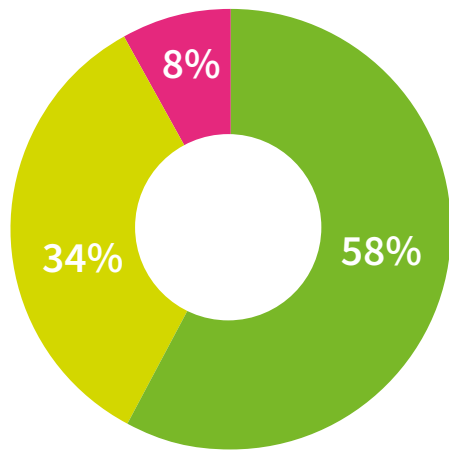


Only 36% of respondents reported their doctor or healthcare professional was very helpful when they spoke about their concerns

Supportive Care

Accessing various forms of supportive care can have a positive effect on the physical and emotional well-being of people living with kidney cancer. The 2022 Global Patient Survey revealed that overall, people have a good understanding of their options.

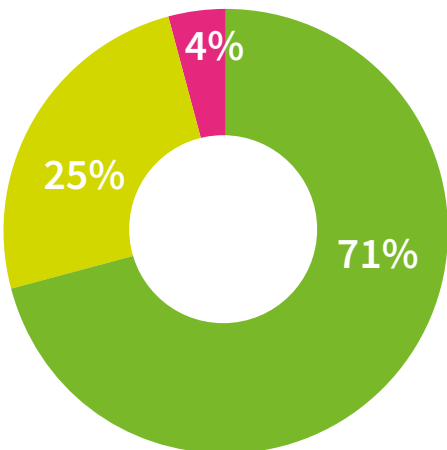
Do you understand the importance of good nutrition:



Yes – 58%
Yes, to some extent – 34%
No – 8%

Learn more about the importance of nutrition: [Kidney Cancer Diet & Nutrition: A guide for patients and their families](#)

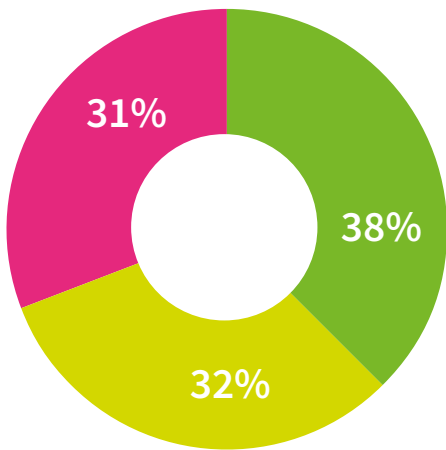
Do you understand the importance of lifestyle choices like avoiding smoking and being active on well-being:



Yes – 71%
Yes, to some extent – 25%
No – 4%

55% of respondents said they were either within or above physical activity guidelines (+150 minutes/week).

Do you understand complimentary therapies like meditation:



Yes – 38%
Yes, to some extent – 32%
No – 31%

About Palliative Care

Palliative care can help protect patients from pain and distress and can support physical and emotional well-being. Yet only 50% of people with advanced kidney cancer reported understanding palliative care.

Better education and access to palliative care will not only help breakdown the stigma associated with this important healthcare support, but it will increase the opportunity for more patients to benefit from it and live better.

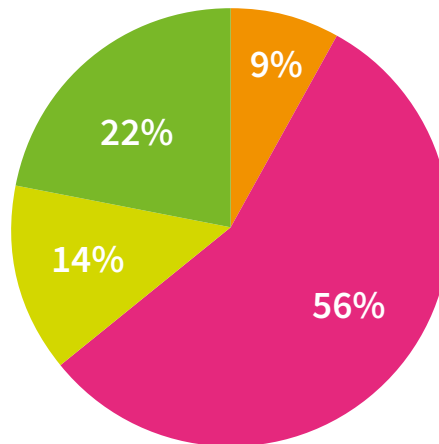
Clinical Trials

It is through clinical trials - and the patients who take part in trials - that advances in treatment and care are made possible. This includes 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.

While the majority of respondents said they were not asked to participate in a clinical trial, more said they were asked in 2022 (**36%**) when compared with the results in the 2020 (**31%**) and 2018 (**30%**) surveys.

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.

Have you ever been asked to participate in a clinical trial?



Yes, when I was first diagnosed – 22%
Yes, when my cancer recurred – 14%
No – 56%
Don't know / can't remember /
don't know of trials in my country – 9%

There are ways to help improve access to clinical trials:

- Opening trials sites in more locations
- Decentralising trials by using technology
- Healthcare teams talking to patients about clinical trials at diagnosis and throughout care
- Patient organisations educating their communities about the importance of clinical trials



“To truly represent kidney cancer patients globally and have trial results that are relevant for all subgroups of people, we need to put a much greater focus on health equity in clinical research. As a start, make sure diverse patient populations are included and remove the barriers to participating in trials.”

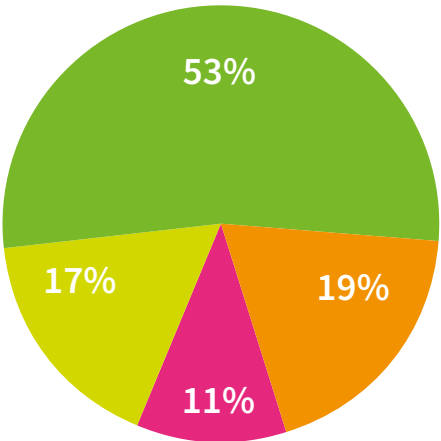
Prof. Toni Choueiri, Dana Farber Cancer Institute, Harvard University, United States

New in 2022: Genetic Testing

Approximately 10-16% of people who are diagnosed with kidney cancer have a hereditary cancer, which means a gene mutation is in most or all of their cells, called a germline mutation. They may have inherited this mutation from their parents or be the first in their family (de novo). Most patients with a germline mutation in a gene that predisposes them to kidney cancer can also pass it on to their children. Treatment approaches for patients with hereditary kidney cancer syndromes is substantially different than sporadic kidney cancer, making it very important to identify patients at risk.

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 other cancers associated with hereditary kidney cancer syndromes, or if the patient has bilateral disease. If an individual meets any of these criteria, they should be offered genetic testing.

Has genetic testing been discussed with you?



No, I have none of the risk factors – 53%
Yes, I have some risk factors, but I was not offered testing– 19%
Yes, I have some of the risk factors and I was offered testing – 17%
Unsure / can't remember – 11%

The 2022 Global Patient Survey found that only half of people who have some of the risk factors were offered genetic testing.

Knowing if a kidney cancer is hereditary can be helpful to patients because it can help a person understand their risk and make more informed decisions about treatment and screening for other cancers. The information can also be shared with family members who may be at a greater risk of cancer.



“Based on the finding in the Global Patient Survey, nearly half of the people who should be considered for genetic testing and counselling are being missed. This is a missed opportunity to not only increase our understanding of hereditary kidney cancer at a broad level, but families are not getting important information that can help them make informed decisions about their health.”

Professor Brian Shuch, University of California, Los Angeles (UCLA), United States

Conclusion

The Global Patient Survey offers a unique view into the experiences of people affected by kidney cancer around the world. After three surveys, the results demonstrate a consolidated baseline of information that identifies the priorities and needs of the kidney cancer community.

The global network of Affiliate Organisations – all patient organisations focused solely or in part on kidney cancer – is well positioned to collaborate and operationalise this data and make improvements in their countries and regions through awareness, education and advocacy.

As patient-driven organisations we expect evidence-based treatment and care of kidney cancer. As such, it is through an evidence-based approach to improving the lives of people with kidney cancer that we can make the greatest difference.

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

The results of the IKCC Global Patient Survey will be used in a variety of ways. First and foremost, the results will help prioritise and support 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 where a more detailed account of the research can be viewed, including variations between:

- Country
- Stage of disease
- Age

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

Acknowledgements

IKCC thanks everyone who contributed to the Global Patient Survey 2022: Mapping the Kidney Cancer Patient Experience Worldwide.

Special thanks to the members of the Project Steering Committee who designed and tested the survey, to Josephine Björqvist who managed the project, and to Picker Institute Europe for execution and analysis of the survey.

We are grateful to 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.

Most importantly, thank you to all the patients and carers who shared their experiences with kidney cancer by completing the survey. Your insights continue to inform the work of kidney cancer 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:



*partial funding



About IKCC

The International Kidney Cancer Coalition (IKCC) is an independent international network of more than 50 patient-focused Affiliate Organisations that focus on kidney cancer. Based in Amsterdam, The Netherlands, the organisation was born from a strong desire among multiple national kidney cancer patient groups to network, collaborate and share knowledge and experiences to ultimately magnify the voices of kidney cancer patients globally.

Kidney cancer is a global issue. Every year, an estimated 431,000 people worldwide will be diagnosed with kidney cancer.¹ 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 and shared decision-making.

From September to November 2022, the survey was conducted in 15 languages in 39 countries. It was completed by kidney cancer patients and carers identified by IKCC 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.

1) Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A (2018). Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality world-wide for 36 cancers in 185 countries. CA Cancer J Clin. 68(6):394–424. <https://doi.org/10.3322/caac.21492> PMID:30207593



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