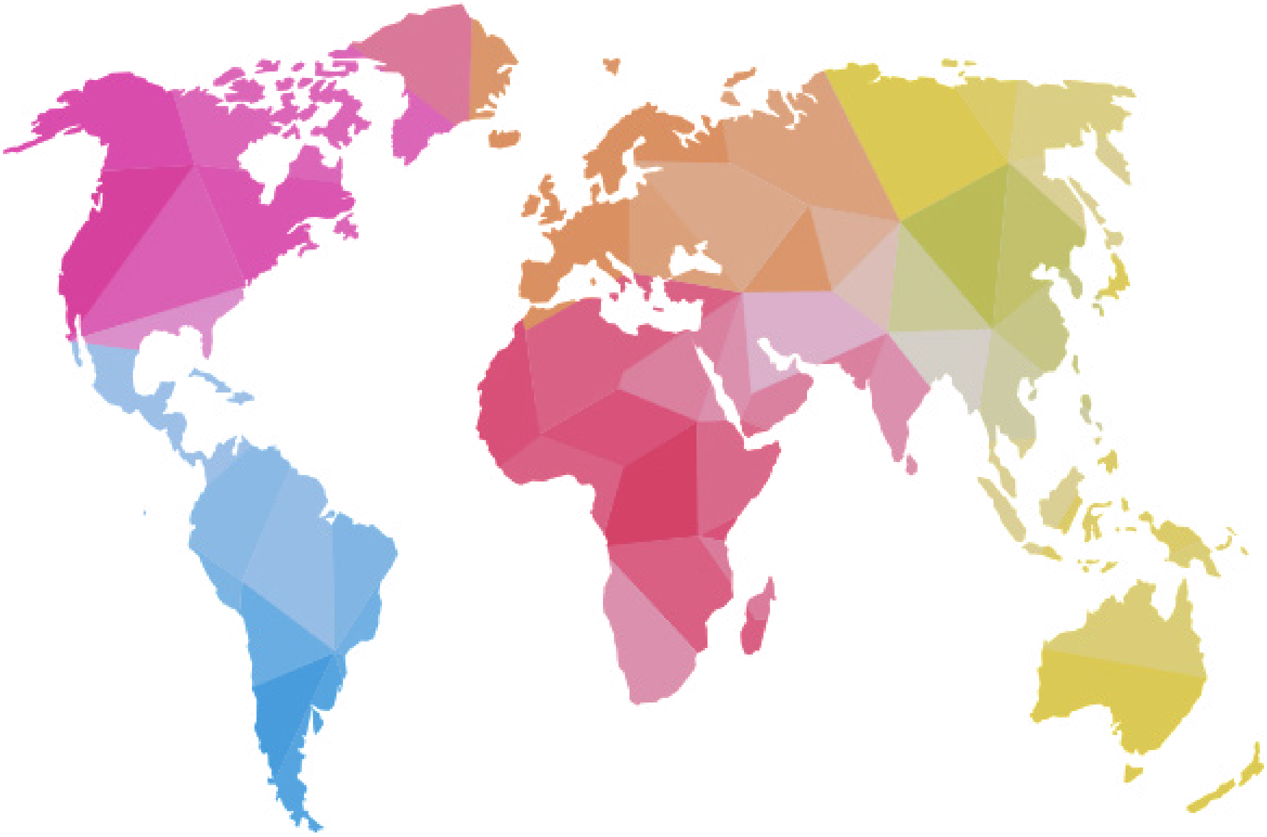
IKCC
International Kidney Cancer Coalition

GLOBAL PATIENT SURVEY

Mapping the Kidney Cancer Patient Experience Worldwide

2025 Highlights Report



Generating evidence to help improve kidney cancer research, treatment, care and survivorship.

Table of Contents

A message from the Steering Committee

On behalf of all the patients and carers worldwide who completed the survey, we are pleased to share the 4th edition of the *Mapping the Kidney Cancer Patient Experience Worldwide Highlights Report*, based on the results of the 4th biennial IKCC Global Patient Survey on Kidney Cancer.

The IKCC Global Patient Survey on Kidney Cancer is the only survey that measures the real-world experiences of people affected by kidney cancer worldwide. It is available in 16 languages to capture a broad global perspective and is administered by Picker Institute Europe, an international health and social charity, to ensure credibility and impartiality in the results. The survey helps identify how the patient experience is changing over time.

Since 2018, every two years the Global Patient Survey benchmarks the patient experience to monitor trends, identify best practices and explore geographical differences and unmet patient needs. It is focused on kidney cancer diagnosis, knowledge, quality of life, shared decision-making and clinical trials. New questions related to biomarker testing and kidney function were added to this edition.

Through the collaboration of Partner Organisations and the global kidney cancer community, a total of 2,677 patients and carers from 46 countries completed the survey between September and November 2024, surpassing the total number of respondents in the 2022 survey by 19%.

In this report you will find the overall highlights of the survey. We are excited to report some areas of positive progress since 2018. Specifically, there is significant improvement in patients' knowledge and understanding of their diagnosis, which allows them to be better informed and engaged partners in their care. Globally, there is also the most positive response about shared decision-making since the survey began, driven by significant improvements in some countries. Global and local education and advocacy efforts are having traction and should be celebrated.

However, other results uncover many areas where there is still much more work to be done. Geographic disparities and inequities remain and need to be addressed. We see this as an opportunity for more collaboration as well as new thinking. How can we better collaborate and learn from countries that have achieved this progress to share and spread their successes? What can we learn from other patient organisations – other cancers or other disease areas – that have overcome some of our challenges? As you read the pages of this report, we hope you are inspired to join our efforts to take on these challenges.

Finally, a tremendous thank you to everyone who contributed to the 4th biennial Global Patient Survey on Kidney Cancer. We are especially grateful to the patients, carers and survivors from around the world who took the time to share their experiences and insights – you are helping to shape the future of the kidney cancer experience.

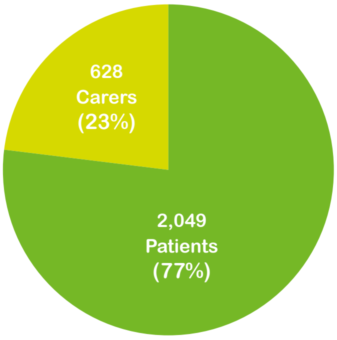
The IKCC Global Patient Survey Steering Committee

About the Survey Respondents

The 4th Global Patient Survey had 2,677 respondents from 46 countries.

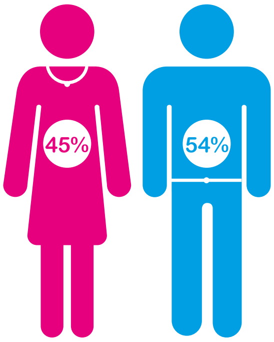
Top responding countries included Italy (12%), Japan (10%), Canada (10%), Republic of Korea (9%), Germany (8%), the United States (8%), France (8%), United Kingdom (7%), Mexico (5%), Türkiye (5%) and India (4%).

Patients vs Carers



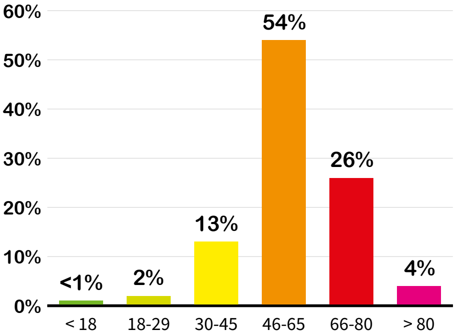
The number of respondents increased by 19% compared to the last survey.

Woman vs Men



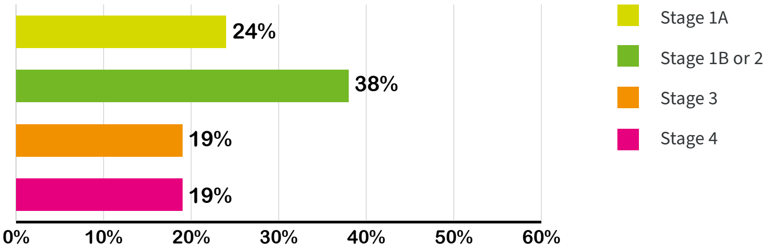
<1% of respondents said another gender
<1% preferred not to say

Age of Respondents



While the age distribution generally reflects diagnosis in the general population[1], respondents over 66 years increased from 13% in 2022 to 30%.

Stage of Kidney Cancer at Diagnosis



At the time of completing the survey 51% of respondents reported no evidenece or disese or cured and 36% of respondents reported living with metastatic kidney cancer.

Kidney Cancer Subtype

62%	Clear cell renal cell carcinoma	2%	Benign growth	1%	Wilms tumour
6%	Papillary renal cell carcinoma	1%	Renal medullary	<1%	Collecting duct renal cell carcinoma
5%	Chromophobe renal cell carcinoma	1%	Renal sarcoma	5%	Other(*)
2%	Unclassified renal cell carcinoma	1%	Transitional cell carcinoma	10%	Don't know / was not told
2%	Von Hippel-Lindau Syndrome (VHL)	1%	Xp11 translocation type		

Twice as many people did not know their subtype compared to the last survey in 2022 (10% vs 5%). This can affect prognosis and treatment options.

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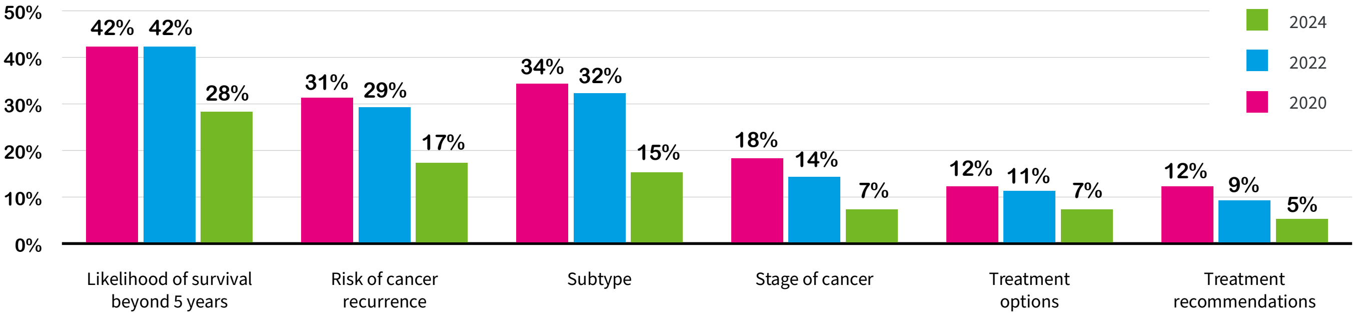
[1] Shuch B, et al. J Clin Oncol. 2014 Feb 10;32(5):431-7

(*)Free-text entry analysis revealed most responses represented more specific RCC histologies such as FH-Deficient RCC, mixed pathologies, or with added notes of Rhabdoid or Sarcomatoid features.

Knowledge and Understanding

When people better understand the details of their diagnosis, they are more empowered to participate in decisions about their treatment and care. Results of the Global Patient Survey revealed improvements in respondents' understanding the details of their diagnosis compared to previous surveys.

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



> *"Both globally and at a local level, we have been working to improve health literacy and empower patients to seek more information about their kidney cancer diagnosis. These findings are promising and our efforts are generating results, but there is still opportunity to facilitate learnings between countries to help close these gaps worldwide."*
>
> – Deb Maskens, patient advocate, Canada

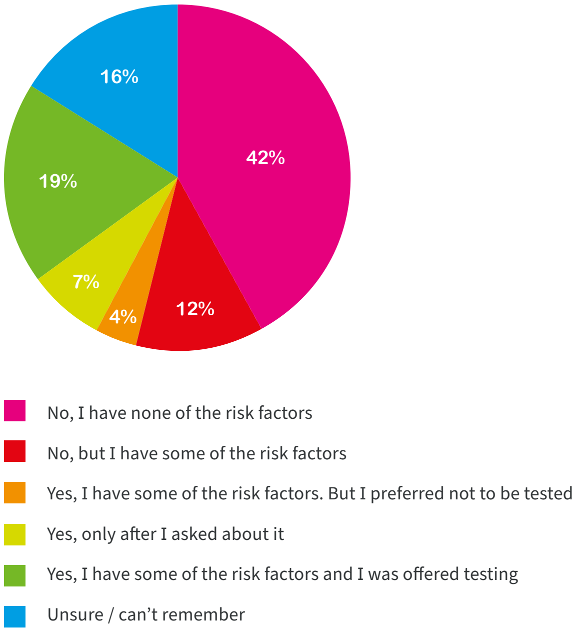
Genetic Testing

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).

The chances of a kidney cancer being hereditary increases with different factors. When the cancer is diagnosed in someone 46 years or younger, when there is a family history of kidney cancer or other cancers associated with hereditary kidney cancer syndromes, with rare variant kidney cancers, or if the patient has bilateral disease. If an individual meets any of these criteria, they should be offered genetic testing.

The EAU guidelines provide more details (*).

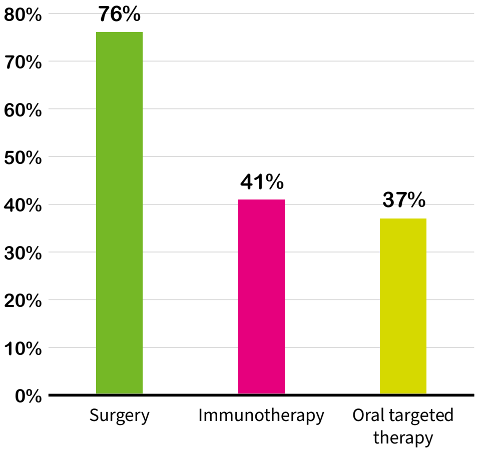
Was genetic testing discussed with you?



(*) Reference: European Association of Urology Guidelines: Renal Cell Carcinoma: https://uroweb.org/guidelines/renal-cell-carcinoma/chapter/references

Kidney Cancer Treatment

Treatment Received for Kidney Cancer

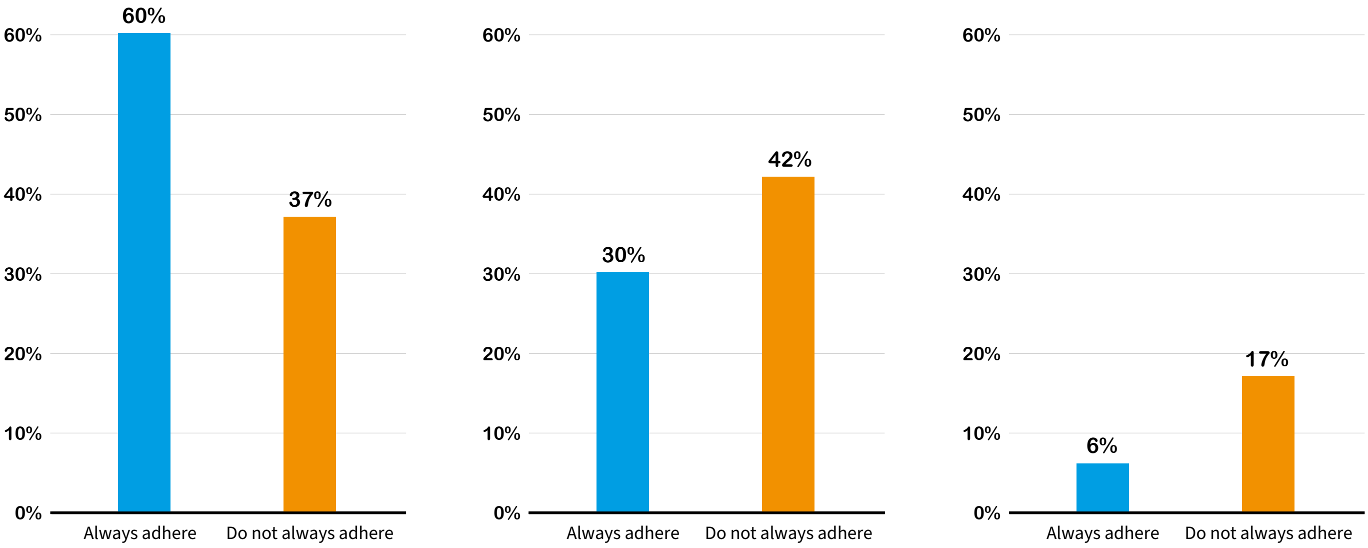


Treatment options for kidney cancer have expanded in recent years. According to the Global Patient Survey, 96% of respondents have received at least one type of treatment, with 76% reporting surgery, 41% immunotherapy and 37% oral targeted therapies.

When a treatment is self-administered and taken at home, such as oral targeted therapies, adhering to the medical instructions is important. Low adherence, such as missing doses or not taking the right number of pills, can lead to poorer health outcomes like disease progression and lower quality of life. Reasons given for not following the prescribed treatment dose included to reduce side effects (64%), not feeling well (43%), interference with plans (31%) and running out of medication (21%).

The survey results also noted that medication adherence is higher among people who say they are ‘definitely involved’ in their treatment decisions, making another strong endorsement to improve shared decision-making in kidney cancer.

Adherence to Oral Targeted Therapy



Definitely involved in treatment decisions

Involved to some extent in treatment decisions

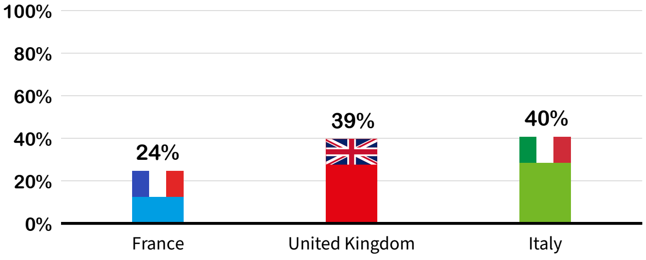
Wanted to be more involved in treatment decisions

Barriers to Treatment

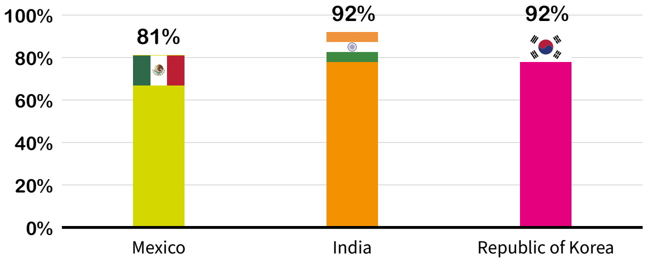
The Global Patient Survey helps identify the barriers people face when accessing treatments. Globally, 55% of respondents said they faced a barrier that affected their treatment choice. The top global barriers were cost of treatment (23%) and waiting times for treatment (22%).

However, it is important to note that patients in some countries disproportionally face more barriers to treatment. Since the first global survey in 2018, patients in France have consistently reported facing the fewest barriers to kidney cancer treatment.

Percent of People who Faced Barriers to Treatment



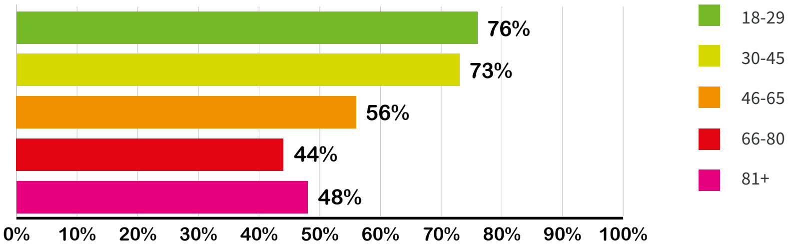
Countries with the fewest barriers to treatment



Countries with the most barriers to treatment

Younger people also faced the most barriers to treatment. The survey showed 76% of the youngest group of patients (18 – 29 years) faced barriers to their treatment, compared to fewer than 50% of people over 66 years. The most common barrier for young patients was cost of treatment (48%).

Percent of People who Faced Barriers to Treatment by Age



Younger patients (18 – 29 years) reported experiencing lower levels of shared decision-making and more barriers to treatment.

Looking Ahead: Biomarker Testing

Unlike many other types of cancer, there are currently no known biomarkers to guide kidney cancer detection or treatment. However, several biomarkers are being tested for future use. To help prepare for when that time comes, the Global Patient Survey asked respondents about their willingness or hesitation to using biomarker testing to help guide treatment choices.

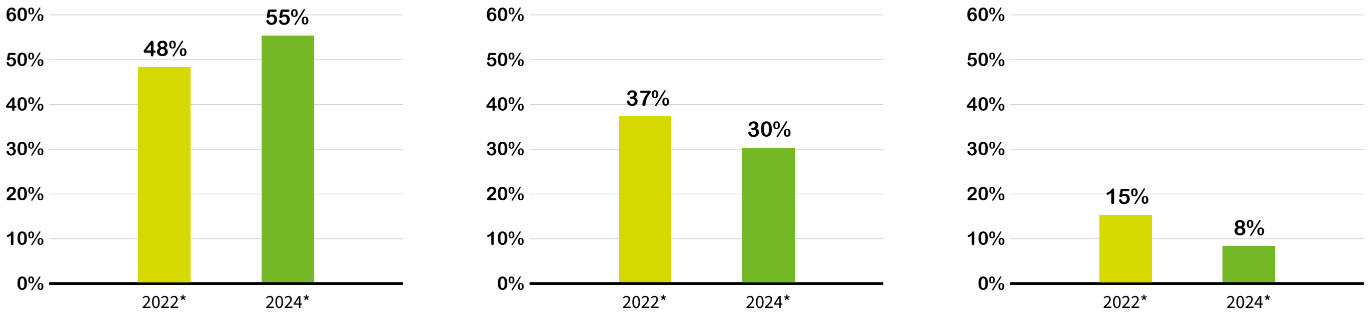
The survey found fewer than one-third (29%) of people would trust the scientific process using biomarker testing. Another 22% said they had some reservations and questions but generally trust the process, and the remaining respondents (48%) either had concerns or did not know.

These early learnings about the understanding and confidence in biomarker testing in the kidney cancer community indicates a strong need for high-quality information and education resources for patients and carers to build trust and confidence.

Shared Decision-Making

Shared decision-making is a core pillar of patient-centred healthcare, central to the notion that patients should have the opportunity to be involved in their treatment decision-making as much as they want. For the first time the majority of patients (55%) said they were definitely as involved in their treatment plans as they wanted to be, 30% answered to some extent and only 8% said no. This is the most positive response since the survey began in 2018.

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



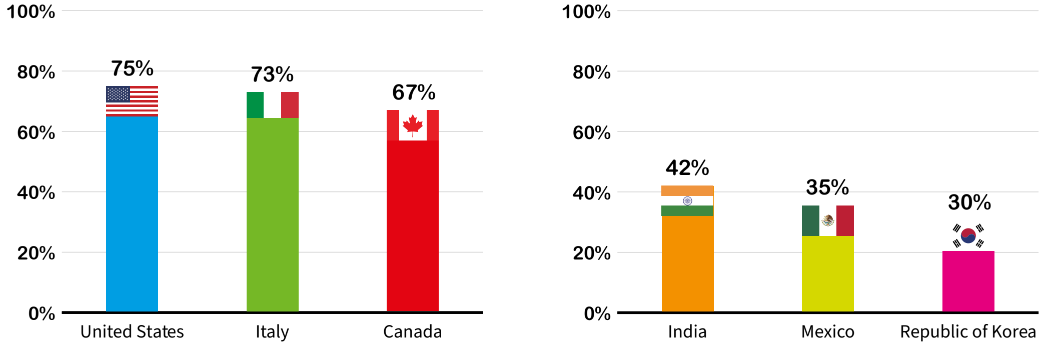
Yes, definitely

Yes, to some extent

No

Despite these positive findings, there is still a wide variance in shared decision-making between countries.

‘Definitely Involved’ in Treatment Decisions



*Year of data collection

Countries with the most involvement

Countries with the least involvement

Overwhelmingly, respondents said they are turning to others to help them make treatment decisions. The top answers when asked who helped make treatment decisions included surgeon or specialist (59%), partner or spouse (46%), children (17%), friends (13%) and patient organisations (12%). Only 8% of people said they made decisions alone.

Improving Shared Decision-Making:

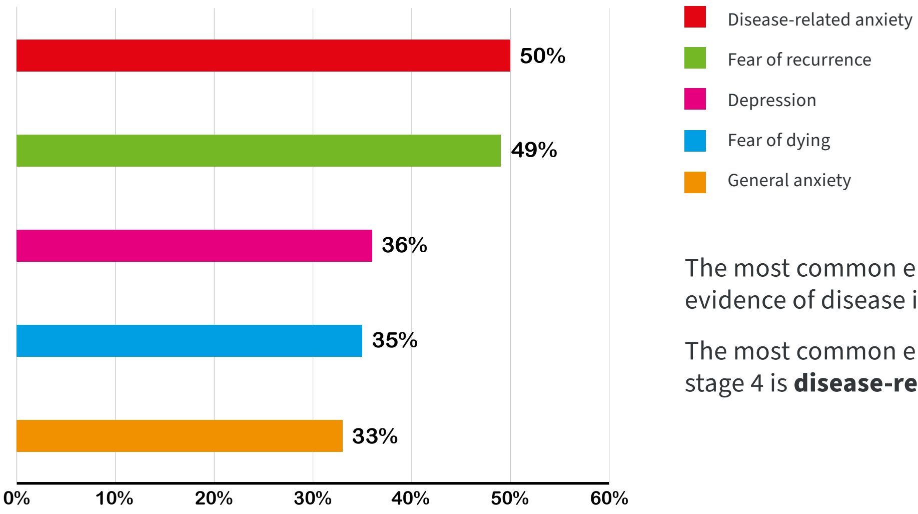
To help close the gaps in shared decision-making, IKCC has created the *My Treatment, My Choice Decision Aid* series, an educational resource to help patients and healthcare professionals make decisions together that reflect the patient’s preferences, goals, values and personal circumstances. All six patient decision aids can be downloaded at https://ikcc.org/kidney-cancer-decision-aid-my-treatment-my-choice/.

Quality of Life

Emotional Wellbeing

In addition to the physical impacts of a kidney cancer diagnosis, people are also experiencing issues related to their emotional wellbeing. The Global Patient Survey found that 85% of patients had experienced an impact to their emotional wellbeing in the past 12 months.

Most Common Emotional Impacts of Kidney Cancer

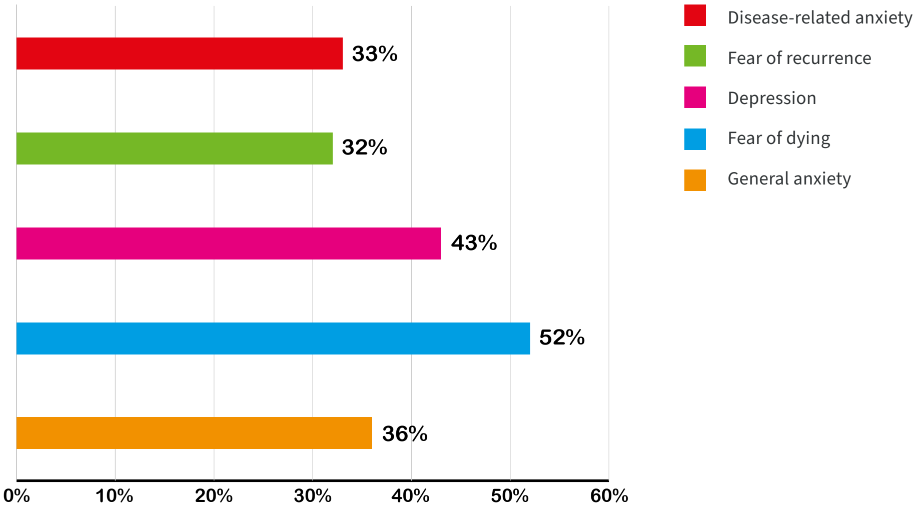


The most common emotional effect for people with no evidence of disease is **fear of recurrence**.

The most common emotional effect for people stages 1 – stage 4 is **disease-related anxiety**.

Experiencing emotional effects from a cancer diagnosis is normal, but there are ways for people to ask for help and for healthcare teams to help addressed them. However, the Global Patient Survey revealed that many people are not talking to any healthcare professional about their challenges.

Percent of People with Emotional Impacts who did Not Speak to Their Healthcare Team:



Palliative Care

The goal of palliative care is to help protect patients from suffering and to support their best possible physical and emotional wellbeing. It helps treat both symptoms of cancer and cancer treatment. People with early access to palliative care have been found to have lower symptom burdens and better understanding of their illness, and families report better outcomes in terms of grief and bereavement.

However, according to the Survey, there are gaps in understanding palliative care. Despite international guidelines for early introduction of palliative care for people living with stage 4 kidney cancer, only 26% of people with advanced disease had a complete understanding of it.

Patient Organisation Support

Most people diagnosed with kidney cancer face challenges to their quality of life and there is a role for patient organisations to offer education, support and community. Nearly half of respondents (47%) said they used a patient group and found it helpful or somewhat helpful. The most popular resources included websites, printed information, online support groups, and in-person support groups. Furthermore, when asked what they would like more access to, respondents said emotional support in the forms of counselling (26%), in-person support groups (26%) and online support groups (21%).

> ***“Patient organisations are well positioned to help close the gaps in patients’ emotional wellness needs, especially when so many healthcare systems are under pressure with limited time and resources. As a global network of patient organisations, we aim to complement the work of healthcare teams by providing credible, evidence-based information and resources that support emotional needs.”***
>
> – Olivier Exertier, Executive Director, IKCC

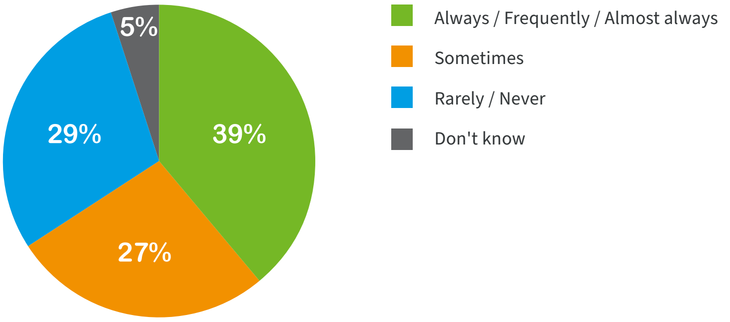
New in 2025: Kidney Function

For the first time, the Global Patient Survey on Kidney Cancer asked people about their kidney function, both before and after their kidney cancer diagnosis, and how they manage their kidney health.

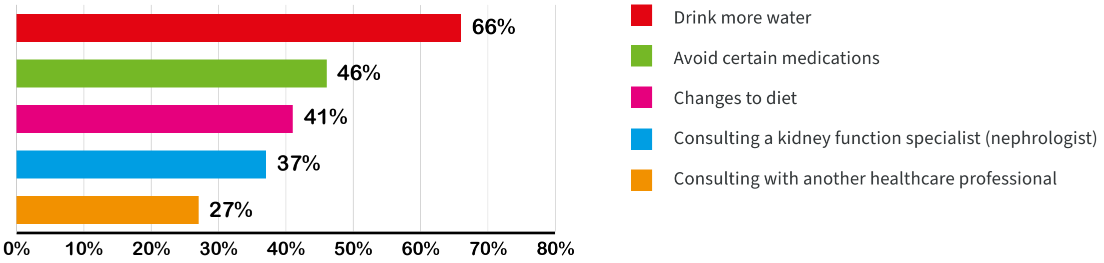
According to the survey, 21% of people said they had kidney function issues (detected in blood or urine) before their kidney cancer diagnosis. When asked about changes resulting from cancer treatment, 39% said their kidney function changed. Three in 5 respondents (61%) said they experienced kidney-related issues. Globally, the most common issues were reduced kidney function / high creatine (39%) and protein in the urine (21%), followed by kidney cysts (14%) and kidney stones (10%).

Significant levels of concern about kidney function were reported in 39% of patients saying that they were always, frequently or almost always concerned about their kidney function, and yet only 27% felt they had enough information about best managing kidney function after a kidney cancer diagnosis. Nearly all respondents (91%) are taking steps in attempts to manage their kidney function.

How often are you concerned about your kidney function?



Activities for Managing Kidney Function



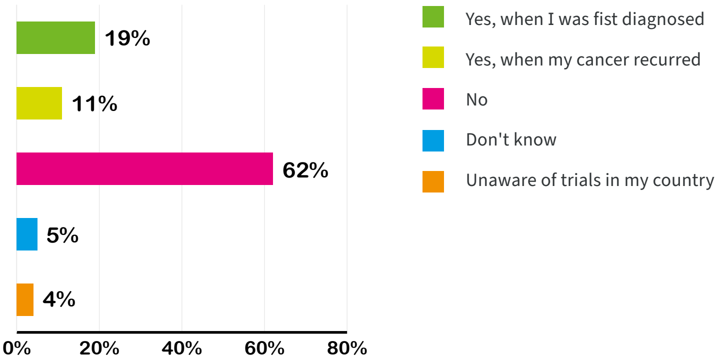
> ***“Kidney function issues concern many people with kidney cancer, so we have a duty to make sure that people in our care have the best evidence-based information available to help them make effective decisions. Keeping hydrated and avoiding certain medications, such as nonsteroidal anti-inflammatories without prescription, is important, but recommendations should be based on discussions with a physician that considers the individual’s comorbidities, dietary habits, smoking status, and physical activity.”***
>
> – Prof. Stênio de Cássio Zequi, IKCC Medical Advisory Board Chair, Brazil

Clinical Trials

Clinical trials look at new ways to prevent, detect, or treat disease to advance kidney cancer care. Participating in a clinical trial can be a way to access a new or otherwise unavailable treatment.

Only 30% of people were asked by a healthcare professional to participate in a clinical trial. This is fewer people when compared to the 2022 and 2020 surveys (36% and 31% respectively). However, when asked, 63% said yes and participated, and another 20% agreed but did not qualify for the trial.

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

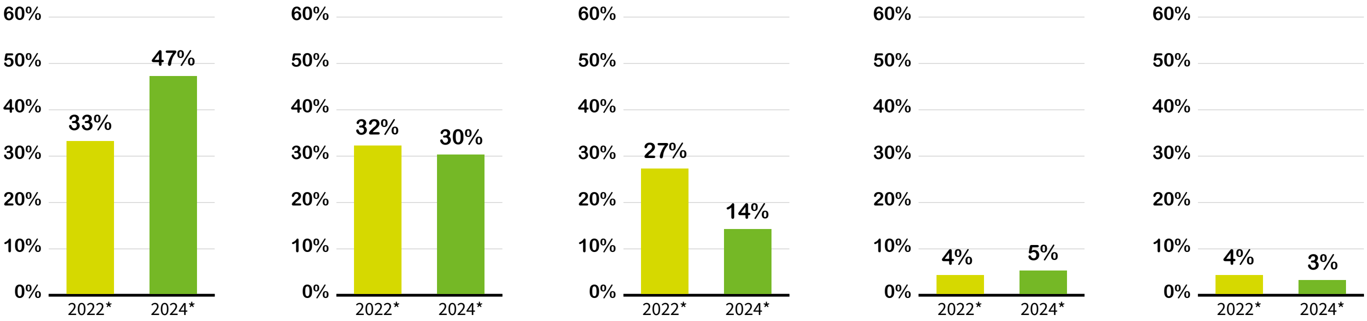


Top Reasons for Participating in a Clinical Trial:

- My doctor recommended it - **64%**
- Thought it might be better care – **53%**
- Wanted to help kidney cancer research – **48%**

When asked about their level of satisfaction participating in a clinical trial, overall respondents indicated they were more satisfied than in the previous survey. Those who reported less than 'Satisfied' still represent approximately 1 in 5 clinical trial participants (22% in 2024, down from 35% in 2022).

Clinical Trials Experience



Very satisfied

Satisfied

Neither satisfied or dissatisfied

Dissatisfied

Very dissatisfied

*Year of data collection

> ***"We believe when patient values are incorporated from clinical trial inception into protocol design and execution, we are able to achieve more meaningful results for patients and improve the patient experience for those who choose to participate."***
>
> – Dr Eric Jonasch, IKCC Board Chair-Elect, United States

Conclusion

The IKCC Global Patient Survey on Kidney Cancer is foundational to our evidence-based approach to improving the lives of people living with kidney cancer. With this information, IKCC and local Partner Organisations can accurately and effectively represent patients' perspectives, insights and needs, and help empower the kidney cancer community through advocacy, awareness, information and research.

Successes highlighted within the findings of the 4th biennial IKCC Global Patient Survey signal that globally, our collective efforts across the kidney cancer community are having a positive impact. Significant efforts have been put into patient knowledge and shared decision-making, and we should collectively be proud of what has been achieved.

However, this is not a moment to rest, but one to be energised by what is possible. We must look for ways to extend these successes to more communities, more countries, and to more areas of unmet patient needs. We can do this through collaboration, learning from each other and partnering with other organisations who have pursued similar change. The survey shows we have more work to do.

This is our commitment as a global coalition, and we hope you will join our efforts. Because it is the sum of our strengths that make an impact for people with kidney cancer around the world.

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

The results of the IKCC Global Patient Survey are used in a variety of ways. First and foremost, the results help prioritise and support programs and initiatives for IKCC globally and locally for Partner Organisations to inform their work. The results of the survey are used to identify trends and measure progress towards 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 for the participants and the sponsors of the survey, including variations between:

- Country
- Stage of disease
- Subtype (Clear Cell RCC, Non-Clear Cell RCC, Other)
- Age
- Gender

Country-Specific Reports are also available when more than 100 people completed the survey. Countries include: Canada, France, Germany, ndia, taly, Japan, Mexico, the Republic of Korea, Türkiye, the United Kingdom and the United States.

Countries who achieved more than 100 responses in 2022 had the opportunity to include 5 country-specific questions related to local topics of interest. These additional questions and the findings can be found in those Country-Specific Reports.

Acknowledgements

IKCC thanks everyone who contributed to the IKCC 2025 Global Patient Survey on Kidney Cancer. Special thanks to the members of the Steering Committee (listed below) who designed and tested the survey and led the initiative, to Shannon Bolden who managed the project, and to Picker Institute Europe for execution and analysis of the survey.

Thanks to the collective efforts of Partner Organisations who helped in creating the survey, adapting it to local regions and promoting the survey to patients and carers in your community.

Most importantly, thank you to all the patients and carers who shared their experiences with kidney cancer by completing the survey and informing the work of kidney cancer organisations worldwide. Without your participation this initiative would not be possible.

The IKCC Global Patient Survey Steering Committee

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Carlos Castro (Deceased)
Asociación Ale, Mexico

This project was funded by the following industry partners in accordance with the IKCC Code of Conduct Governing Funding. Sponsors have not been involved in the Global Patient Survey at any stage.

Dedication

This report is dedicated to the late Carlos Castro Sánchez, a member of the Global Steering Committee for the IKCC biennial survey since its inception. Carlos was a person of great altruism, and together with his family, founded the Ale IAP Association, an IKCC Partner Organisation, in memory of his deceased grandson Alejandro in 2004.

Carlos will be greatly missed by the many people he has touched in the global kidney cancer community.

About IKCC

International Kidney Cancer Coalition (IKCC) is the only global patient-driven organisation focused on kidney cancer. The Coalition of Partner Organisations from around the world collaborate, share and learn from each other with the goal of reducing the burden of kidney cancer worldwide. Together we are making a global impact by improving research, treatment, care and survivorship.

Our work is grounded in evidence that reflects the experiences of patients, carers and healthcare professionals. This information is shared and incorporated when decisions are made about kidney cancer research, treatment and support. This knowledge and understanding also ensures education, awareness and advocacy programs respond to the needs of people living with kidney cancer.

Kidney cancer is a global issue. Since the 1970s, the global incident rates of kidney cancer have been increasing[2]. In 2024, the worldwide incidence is estimated at 434,840 and approximately 155,953 people die from the kidney cancer every year[3]. It is projected that the incidence will continue to rise with an estimate of 647,361 new cases in 2050[4]. When local efforts are strengthened with a global approach, we can have the greatest impact on improving health equity and patient outcomes for people with kidney cancer.

About the IKCC Global Patient Survey on Kidney Cancer

To improve collective understanding, IKCC has collaborated with Partner Organisations to establish a biennial Global Patient Survey on Kidney Cancer, which launched in 2018. The survey is open to anyone who has received a diagnosis or is a carer. The results gathered help patient organisations locally and IKCC globally create education, awareness and advocacy programs that respond to the needs of people affected by kidney cancer. Past Global Patient Survey results have been published in scientific manuscripts, presented at medical conferences, informed educational resources and helped guide World Kidney Cancer Day campaigns.

From September to November 2024, the survey was available online in 16 languages. It was promoted by IKCC Partner Organisations, affiliated clinicians and allied healthcare professionals, as well as shared on IKCC's social media channels and website. The survey achieved 2,677 patient and carer responses from 46 countries. The survey was developed, and data were independently analysed by Picker Institute Europe, a 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, please contact:

info@ikcc.org.

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[2] J Clin Oncol. 2018 Dec 20; 36(36): 3574–3581.

[3] Ferlay J, Ervik M, Lam F, Laversanne M, Colombet M, Mery L, Piñeros M, Znaor A, Soerjomataram I, Bray F (2024). Global Cancer Observatory: Cancer Today. Lyon, France: International Agency for Research on Cancer. Available from: https://gco.iarc.who.int/today, accessed 19 February 2025.

[4] Global Cancer Observatory. Available from: https://gco.iarc.fr/tomorrow/en/dataviz/tables?cancers=29&years=2050, accessed 19 February 2025.

International Kidney Cancer Coalition

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