



**IKCC**  
International Kidney  
Cancer Coalition

# 2631P: Unmet Needs & Disparities in Kidney Cancer (KC): International Kidney Cancer Coalition (IKCC) Global Patient Survey (GPS)

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## Background

- Over 434,800 patients worldwide were diagnosed with kidney cancer (KC) in 2022. The incidence of KC continues to increase globally, escalating the burden on patients, families, and healthcare systems<sup>1,2</sup>
- Shared decision making (SDM) and open communication between patients, carers, and healthcare providers (HCP) is critical to improve patient outcomes and reduce emotional burdens<sup>3</sup>
- Ensuring patient adherence to KC medication is a challenge that can be impacted by various interconnected patient-disease-related factors<sup>4</sup>
- Clinical trials play a vital role in improving patient care and advancing medical knowledge<sup>5</sup>
- Since 2018, the IKCC's biennial global patient survey has captured insights on KC diagnosis, management, and burden to identify unmet needs and regional differences
- Findings related to patient involvement in SDM, oral targeted therapy adherence, emotional impact of KC, and clinical trial participation are presented

## Methods

### Survey development

- IKCC conducted a biennial survey of KC patients and carers
- It was developed by the IKCC steering committee, including patient advocates, medical experts, and the Picker Institute (UK)
- The survey was cognitively tested and offered in 16 languages

### Survey availability and promotion

- The survey was available online and in hardcopy (for countries with limited internet access) from September 23, 2024, to November 15, 2024
- It was hosted on Qualtrics via an open link and distributed by the IKCC and Partner Organizations to KC patients, those with a kidney growth, and their carers
- Promotion occurred through IKCC Partner Organizations, healthcare professionals, social media, and websites

### Respondents

- Before starting the survey, respondents were informed of the survey's purpose, voluntary nature, confidentiality, and intended use of results
- No identifiable data were collected
- Aside from required demographics, questions could be skipped
- Routing logic ensured only relevant questions were shown

### Analysis and review

- After the survey closed, data were analyzed in aggregate and via cross-tabulations. Responses not meeting the inclusion criteria were removed
- Data were analyzed for duplicate responses through the open link and Bot Detection

## Results

### Patient characteristics

- Between September 23, 2024, and November 15, 2024, the survey collected 2677 responses from 46 countries (2,049 patients; 628 carers)
  - Overall, 54% were male, and 80% were aged 46-80. Clear cell RCC was the most common diagnosis (62%); 19% were diagnosed at stage 4, and 52% within the past four years (Table 1)
  - Notably, 10% of respondents did not know or were not informed of their KC subtype

Table 1: Global Participant Characteristics

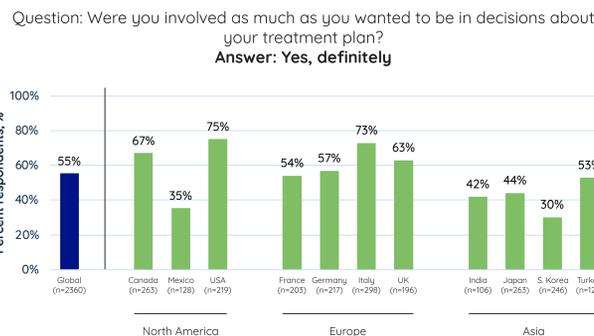
Characteristic		%
Gender, % n=2677	Male	54
	Female	45
Age group, % n=2655	<18 years	<1
	18-29 years	2
	30-45 years	13
	46-65 years	54
	66-80 years	26
	>80 years	4
Stage at diagnosis, % n=2438	1A	24
	1B or 2	38
	3	19
	4	19
Current stage, % n=2157	No evidence or cured	51
	1 or 2	8
	3	6
	4	36

Characteristic	%	
Year of Diagnosis, % n=2655	Prior to 2011	15
	2011-2013	6
	2014-2016	10
	2017-2019	17
	2020-2022	27
	2023-Present	25
Kidney cancer sub-types, % n=2677	Clear cell renal carcinoma	62
	Papillary renal cell carcinoma	6
	Chromophobe renal cell carcinoma	5
	Unclassified renal cell carcinoma	2
	Xp11 translocation type	1
	VHL (Von Hippel-Lindau syndrome)	2
	Renal medullary carcinoma	1
	Collecting duct renal cell carcinoma (Bellini Duct)	<1
	Transitional cell carcinoma (urothelial carcinoma)	1
	Renal sarcoma (NOT renal cell carcinoma with sarcomatoid appearance)	1
	Wilms Tumor	1
	Benign growth	2
	Other	5
I did not receive this information	4	
Don't know / can't remember	6	

### Shared decision making

- Globally, 55% of respondents reported they were involved as much as they wanted to be in decisions about their treatment plan
  - Variations were observed across countries, with respondents from the Republic of Korea (30%) and Mexico (35%) reporting the least involvement (Figure 1)

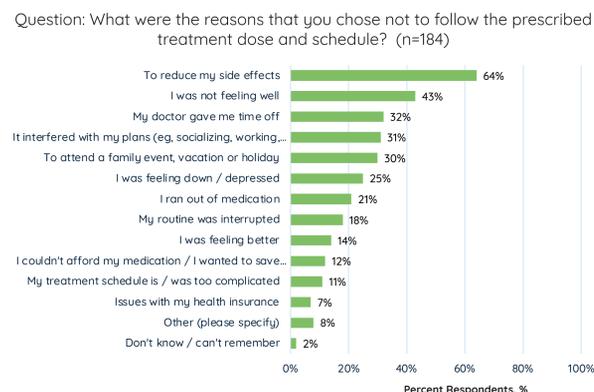
Figure 1: Percent of Patients Who Were Involved As Much as They Wanted to Be in Decision Making, According to Country.



### Oral therapy adherence

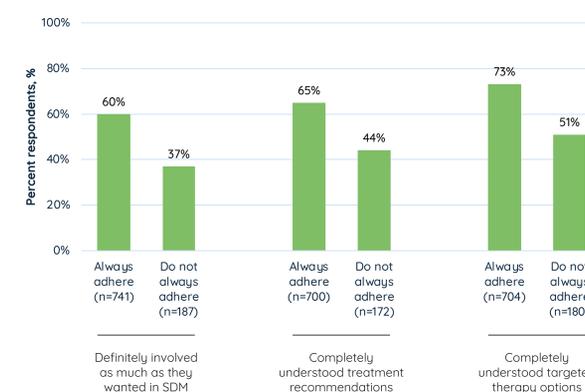
- Across all countries, 79% of the 936 respondents who received oral targeted therapies indicated that they always adhered to them as prescribed, while 21% of respondents did not always adhere
  - The most common reasons cited for non-adherence were to reduce side effects (64%), and not feeling well (43%) (Figure 2)

Figure 2: Global Reasons for Non-Adherence to Oral Targeted Therapies.



- The impact of being involved as much as desired in SDM, and a complete understanding of their treatment recommendations and targeted therapy options on oral therapy adherence was explored
  - Respondents who always adhered to oral targeted therapies were more likely to be involved in SDM and completely understand their treatment recommendations and targeted therapy options (Figure 3)

Figure 3: Relationship Between Treatment Adherence to Oral Targeted Therapies and SDM Involvement and Health Literacy.



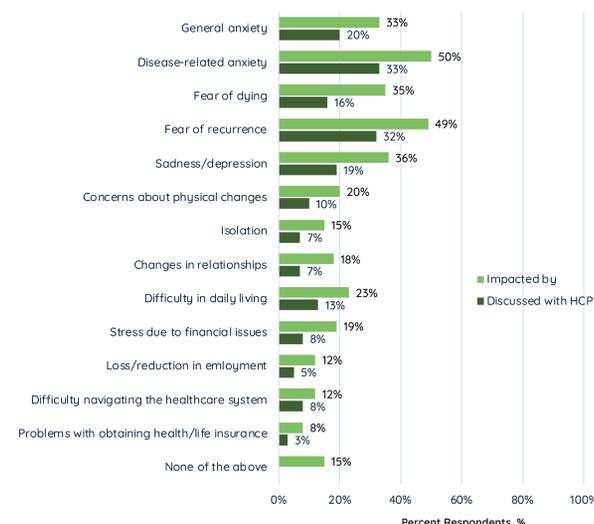
The number of respondents is dependent on individuals answering all the questions used to derive the data.

### Impact on emotional well-being

- In the last 12 months, 85% of patients, globally, experienced an impact to their emotional wellbeing due to KC or a growth (Figure 4)
  - Patients were most likely to experience disease-related anxiety (50%), and fear of recurrence (49%) (Figure 4)
- Patients more commonly discussed disease-related anxiety (33%), fear of recurrence (32%), general anxiety (20%), and sadness/depression (19%) with their HCP (Figure 4)
  - Issues not commonly discussed with an HCP included isolation (7%), changes in relationship (7%), loss/reduction in employment (5%), and problems with obtaining health/life insurance (3%) (Figure 4)

Figure 4: Percent of Patients Who Were Impacted Emotionally by KC and Discussed Their Concern With an HCP.

Question 1: In the last 12 months, have you experienced any of the following issues as a result of your kidney cancer/kidney growth? (n=2353)  
Question 2: Have you ever talked to your doctor or to any other HCP about any of your concerns for the following? (n=2353)



### Participation in clinical trials

- Globally, only 30% of respondents reported an HCP asked them to consider participating in a clinical trial
  - Among the 683 respondents who were asked to participate in a trial, 83% agreed to participate
- The most common reasons respondents agreed to participate in a clinical trial were:
  - My doctor recommended it (64%)
  - I thought it might offer better care (53%)
  - I wanted to help KC research (48%)
- 422 respondents were eligible and participated in a trial
  - 77% reported they were satisfied with the experience
  - 23% were not satisfied with the clinical trial experience

## Conclusion

- Globally, 55% of respondents reported being involved in SDM; however, wide disparities remain across countries
- While approximately 4 in 5 respondents always adhered to their oral targeted therapies, adherence may be improved by optimizing patient education and SDM
- Most patients reported that their emotional wellbeing was impacted by KC, but many concerns were not raised to HCPs
- The majority of respondents (70%) were not asked to consider participating in a clinical trial; furthermore, 1 in 4 who participated in a trial were not satisfied with their experience
- Patient experiences vary significantly by country, presenting opportunities for further investigation and best practice sharing by patient organizations and health care providers

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## Disclosures

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