Knowledge Gaps and Shared Decision Making (SDM) Disparities in Kidney Cancer (KC) Across North America (NA): Results from the International Kidney Cancer Coalition (IKCC) Global Patient Survey (GPS)

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Background

- Shared decision making (SDM) and open communication between patients, caregivers, and healthcare providers (HCP) is critical to improve patient outcomes and reduce emotional burdens[1]
- Barriers to cancer treatment lead to inequities in cancer outcomes and poorer quality of life[2]
- 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 knowledge gaps, treatment barriers, and patient involvement in SDM across North America compared to global responses are reported

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 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 and their caregivers
- 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 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), including Canada (n=266), the USA (n=220), and Mexico (n=131)
  - 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 sub-type

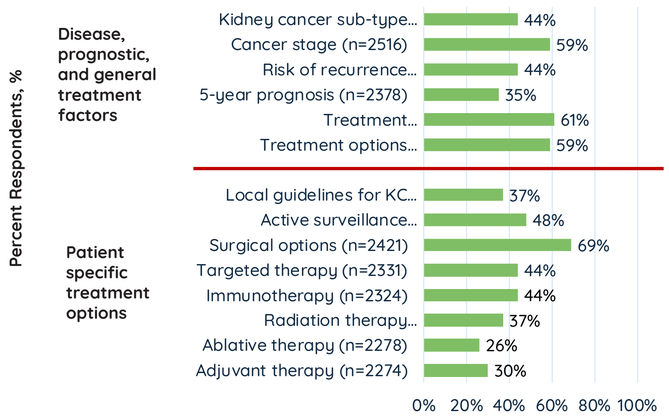
Table 1: Global Participant Characteristics

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**
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**

Knowledge of KC disease and management
- Among global respondents, only 35%–44% completely understood their KC sub-type, risk of recurrence, or 5-year prognosis, while 59%–61% completely understood their tumor stage, treatment options or recommendations **(Figure 1)**
- Only 26%-48% of respondents completely understood specific treatment options, while most respondents (69%) understood surgical options **(Figure 1)**

Figure 1: Percent of Patients Who Completely Understood the Following Disease Characteristics, Prognostic Factors, and Treatments

Question: When planning your treatments, were the following explained in a way you could understand?
Answer: Yes, completely

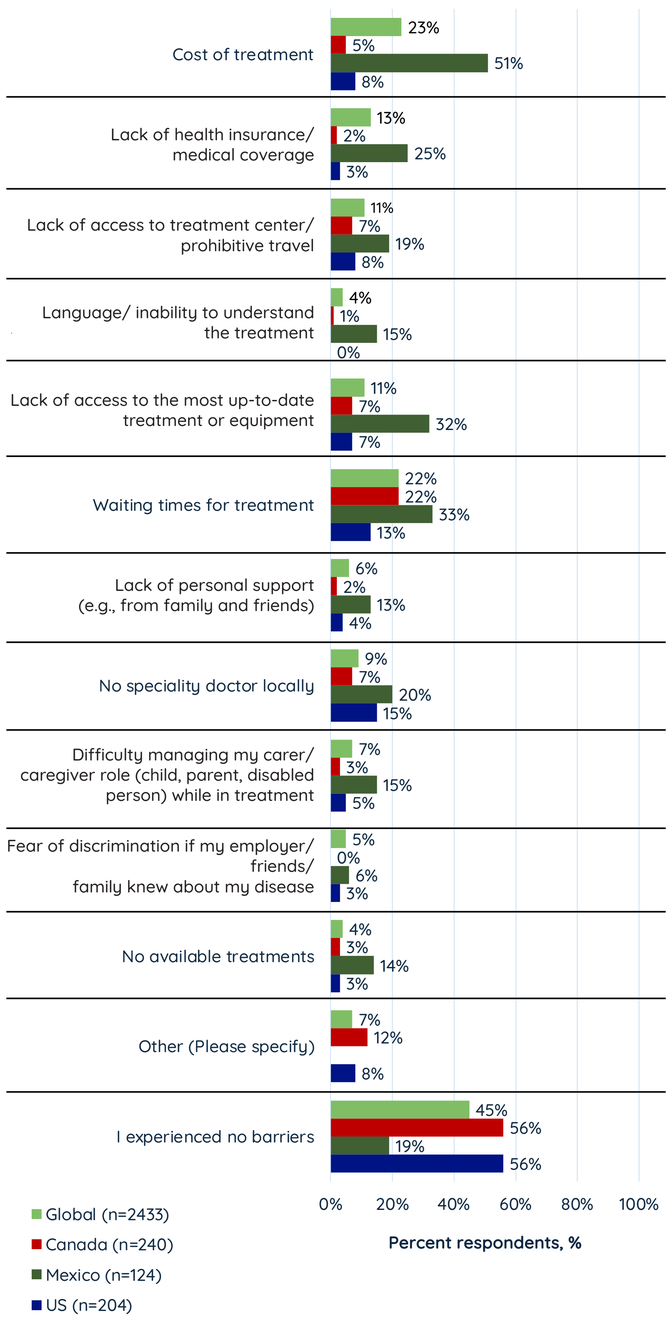


Barriers to treatment
- Globally, 55% of respondents reported at least one barrier to treatment
  - The percentage of respondents in North America who experienced a barrier was: Canada (44%), Mexico (81%), and USA (44%) **(Figure 2)**

The most common barriers in North America were **(Figure 2)**:
- Canada: waiting times for treatment (22%), lack of access to treatment center/prohibitive travel (7%), lack of access to most up-to-date treatment/equipment (7%), no specialty doctor locally (7%)
- Mexico: cost of treatment (51%), waiting times for treatment (33%), lack of access to most up-to-date treatment/ equipment (32%)
- USA: no specialty doctor locally (15%), waiting times for treatment (13%), cost of treatment (8%), and lack of access to treatment center/prohibitive travel (8%)

Figure 2: Barriers to treatment

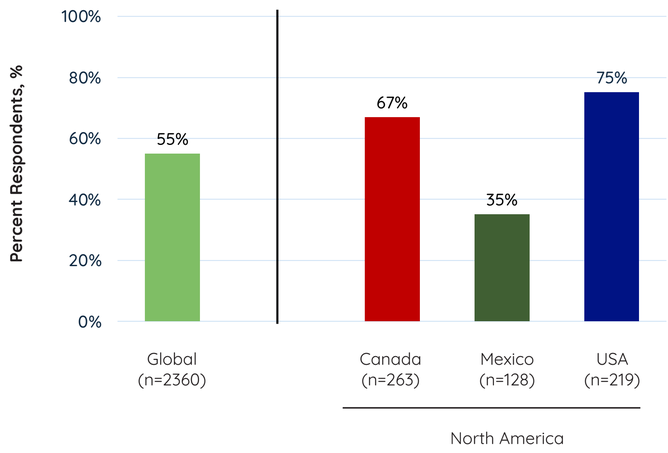
Question: Which barriers (if any) have you experienced that affected your treatment choices for your KC or kidney growth (choose all that apply).



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 Mexico (35%) reporting the least involvement **(Figure 3)**

Figure 3: Percent of Patients Who Were Involved As Much as They Wanted to Be in Decision Making, According to Country.

Question: Were you involved as much as you wanted to be in decisions about your treatment plan?
Answer: Yes, definitely



- Globally, respondents most commonly referred to surgeon/ specialist (59%) and partner/spouse (46%) to help make treatment decisions
- Support sources in each country reported by ≥20% respondents were:
  - Canada: surgeon/specialist (69%), partner/spouse (53%)
  - Mexico: partner/spouse (46%), surgeon/specialist (31%), family doctor (30%), their children (24%), parents (23%), friends/other family members (23%)
  - A: partner/spouse (66%), surgeon/specialist (62%), their children (20%), online resources (20%)

Conclusion

- Most patients do not completely understand their disease, prognosis, or treatment options
- Approximately 2 in 5 respondents in Canada and the USA and 4 in 5 respondents in Mexico experience barriers to KC treatment
- Globally, 55% of respondents reported being involved in SDM; however, wide disparities remain across countries
- Patient experiences vary significantly by country, presenting opportunities for further investigation and best practice sharing by patient organizations and health care providers

References

1. Montori VM, et al. Shared decision-making as a method of care. *BMJ Evid Based Med.* 2022;28(4):213–217.
2. Bourgeois A, et al. Barriers to cancer treatment for people experiencing socioeconomic disadvantage in high-income countries: a scoping review. *BMC Health Serv Res.* 2024;24:670.

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