Treatment Barriers and Shared Decision-Making Disparities in Kidney Cancer Across Europe: Results from the IKCC Global Patient Survey

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Background

- Since 2018, the International Kidney Cancer Coalition (IKCC) has conducted a biennial Global Patient Survey (GPS) to assess patient and carer experiences, identify unmet needs, and guide actions to reduce disparities
- This exploratory analysis of 2025 GPS data assessed variability across Europe on shared decision making (SDM), disease-related knowledge, and treatment barriers, and compared European results with those from the rest of the world (ROW)

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 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

- Results are reported for European countries with >30 respondents; remaining European countries were grouped as "Other European countries"
- After the survey closed, data were analyzed in aggregate and via cross-tabulations. Responses not meeting inclusion criteria were removed. Chi square analysis was performed
- Data were analyzed for duplicate responses through the open link and Bot Detection
- n values represent the number of respondents who answered each question

Results

Patient characteristics

- Between September 23, 2024, and November 15, 2024, the survey collected 2,677 responses, including 1,247 responses from Europe (patients, n=1003; carers, n=244)
  - 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)**

Table 1: Global Participant Characteristics

Characteristic, n (%)		
Gender, % n=2677	Male	1452 (54)
	Female	1210 (45)
Age group, % n=2665	<18 years	13 (<1)
	18-29 years	57 (2)
	30-45 years	349 (13)
	46-65 years	1441 (54)
	66-80 years	705 (26)
	>80 years	100 (4)
Stage at diagnosis, % n=2438	1A	582 (24)
	1B or 2	929 (38)
	3	454 (19)
	4	473 (19)
Current stage, % n=2157	No evidence or cured	1098 (51)
	1 or 2	170 (8)
	3	122 (6)
	4	767 (36)
Year of Diagnosis, % n=2665	Prior to 2011	390 (15)
	2011-2013	163 (6)
	2014-2016	275 (10)
	2017-2019	453 (17)
	2020-2022	719 (27)
	2023-Present	665 (25)
Kidney cancer sub-types, % n=2677	Clear cell renal carcinoma	1669 (62)
	Papillary renal cell carcinoma	163 (6)
	Chromophobe renal cell carcinoma	136 (5)
	Unclassified renal cell carcinoma	65 (2)
	Xp11 translocation type	20 (1)
	VHL (Von Hippel-Lindau syndrome)	58 (2)
	Renal medullary carcinoma	20 (1)
	Collecting duct renal cell carcinoma (Bellini Duct)	11 (<1)
	Transitional cell carcinoma (urothelial carcinoma)	32 (1)
	Renal sarcoma (NOT renal cell carcinoma with sarcomatoid appearance)	15 (1)
	Wilms Tumor	26 (1)
	Benign growth	57 (2)
	Other	133 (5)
	I did not receive this information	107 (4)
	Don't know / can't remember	165 (6)

SDM and knowledge about KC characteristics, prognosis, and treatments

- Respondents from Europe reported more satisfaction with their involvement in SDM than the ROW (P<0.001), with those from Italy reporting the greatest satisfaction with their involvement (73%) **(Figure 1)**
- Respondents across Europe reported significantly higher complete understanding of KC subtype (P=0.048) and KC stage (P<0.001), lower understanding of survival probability (P=0.004), and similar understanding of other parameters than respondents from the ROW **(Figure 2)**

Barriers to treatment

- Overall, treatment barriers were less common in Europe than the ROW (P<0.001), though marked country-level differences were observed **(Figure 3)**
  - Respondents from Poland reported the most barriers (70%), while those from France reported the least barriers (24%)
- The most common barriers across Europe were long wait times, and cost **(Figure 4)**

Figure 1: Percentage of Patients Who Were Involved as Much as They Wanted in SDM

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

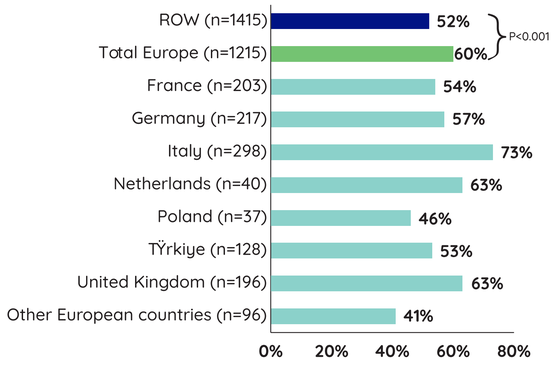


Figure 2: Percentage of Patients Who Had Knowledge of Their KC Characteristics, Prognosis, and Treatments

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

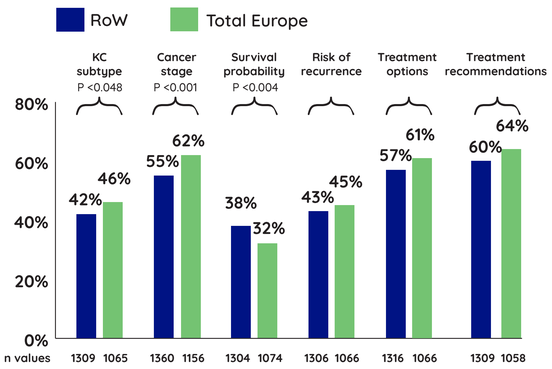


Figure 3: Percentage of Respondents Who Experienced Barriers That Impacted Treatment

Question: Which barriers (if any) have you experienced that affected your treatment choices for your kidney cancer?

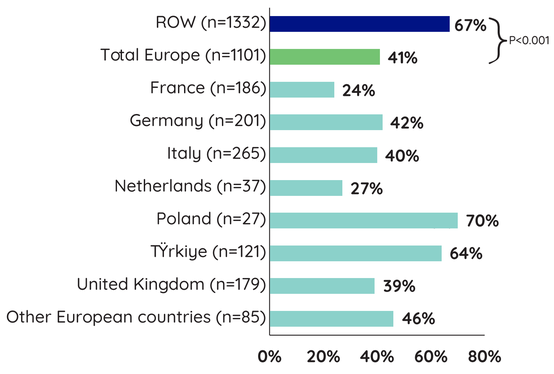
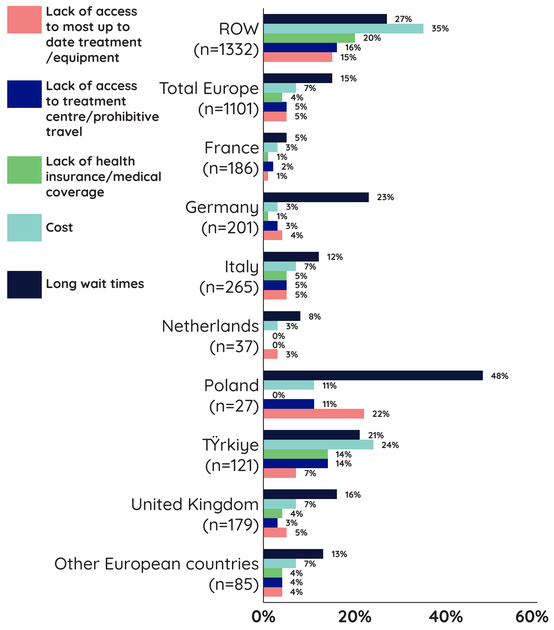


Table 2: Key Barriers Experienced by Respondents



Conclusion

- Improvements are seen in SDM and patient education throughout Europe; however, knowledge gaps and treatment barriers remain
- Despite higher reported SDM involvement in Europe versus ROW, clinically meaningful knowledge gaps and access barriers persist across Europe, with considerable heterogeneity between countries
- These findings underscore the need for enhanced clinician–patient communication, improved patient education, timely access to care, and country-specific interventions to reduce disparities

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