

# 546MO: Knowledge Gaps and Shared Decision-Making Disparities in Kidney Cancer Across Asia

## Results from the International Kidney Cancer Coalition (IKCC) Global Patient Survey

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# DECLARATION OF INTERESTS

## **Murallitharan Munisamy**

- No financial or non-financial interests to declare

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# DECLARATION OF INTERESTS

## Remaining authors

- **Eric Jonasch:** research support from AbbVie, Aveo, Bristol Myers Squibb, Corvus, Merck, Nikang, ProfoundBio, and Telix, and has received honoraria from Arcus, Aveo, Eisai, Exelixis, Ipsen, Merck, Novartis, Nikang, Takeda, and Telix
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# Introduction

## International Kidney Cancer Coalition (IKCC)

- IKCC is the only global patient-driven organisation focused on kidney cancer
- It is a global network of Partner Patient Organisations working together to reduce the burden of kidney cancer locally and globally
- Beginning in 2018, IKCC launched a biennial global patient survey capturing patient insights on KC diagnosis, management, and burden to identify unmet needs and regional differences

# IKCC Global Survey

## Background

- In 2022, globally > 434,800 people were diagnosed with KC<sup>1</sup>
- Incidence of KC continues to increase globally, escalating the burden on patients, families, and healthcare systems<sup>2</sup>
- Findings related to patient barriers to treatment, involvement in SDM, and knowledge of KC disease and management with a focus on Asia are presented

**2,677 patients and carers from 46 countries responded to the survey**

KC, kidney cancer; SDM, shared decision making. | 1. IARC-WHO, Kidney Cancer Statistics; 2. Bourgeois A, et al. BMC Health Serv Res. 2024;24:670

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# IKCC Global Survey

## Methods

- Survey was developed by a Steering Committee including patient advocates, medical experts, and the Picker Institute (UK)
- Distributed in 16 languages by IKCC, Partner Organizations, and HCPs either online or in hardcopy from Sept. 23 – Nov. 15, 2024
- No identifiable patient data was collected, and respondents were informed of the survey's purpose, voluntary nature, confidentiality, and intended use of results

# Global Patient Characteristics

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
Year of Diagnosis, % n=2655	Prior to 2011	15
	2011-2013	6
	2014-2016	10
	2017-2019	17
	2020-2022	27
	2023-Present	25
Stage at diagnosis, % n=2438	1A	24
	1B or 2	38
	3	19
	4	19

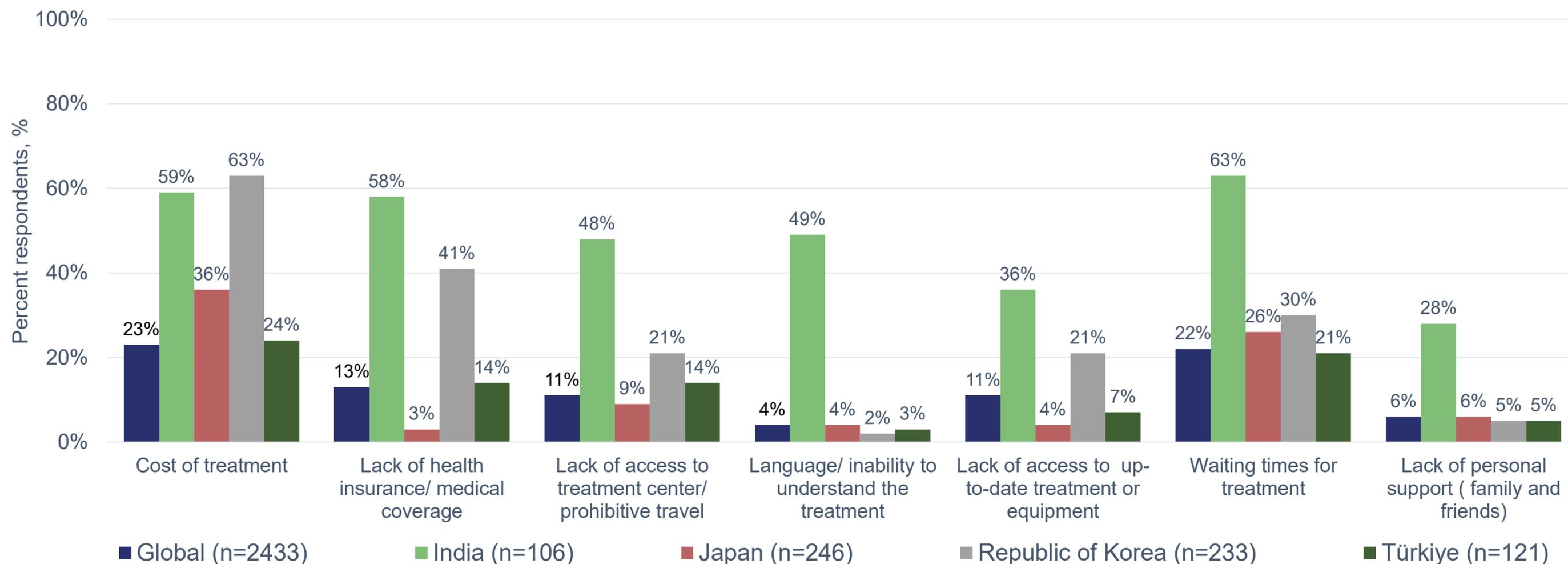
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Current stage, % n=2157	No evidence or cured	51
	1 or 2	8
	3	6
	4	36
Kidney cancer sub-types, % n=2677	Clear cell RCC	62
	Papillary RCC	6
	Chromophobe RCC	5
	Unclassified RCC	2
	Xp11 translocation	1
	VHL (Von Hippel-Lindau)	2
	Renal medullary carcinoma	1
	Collecting duct RCC (Bellini Duct)	<1
	Transitional cell carcinoma (urothelial)	1
	Renal sarcoma (NOT sarcomatoid}	1
	Wilms Tumor	1
	Benign growth	2
	Other	5
	I did not receive this information	4
Don't know/can't remember	6	

# Barriers to Treatment Varied Across Countries

Which barriers (if any) have you experienced that affected your treatment choices for your kidney cancer or kidney growth? (Choose all that apply)

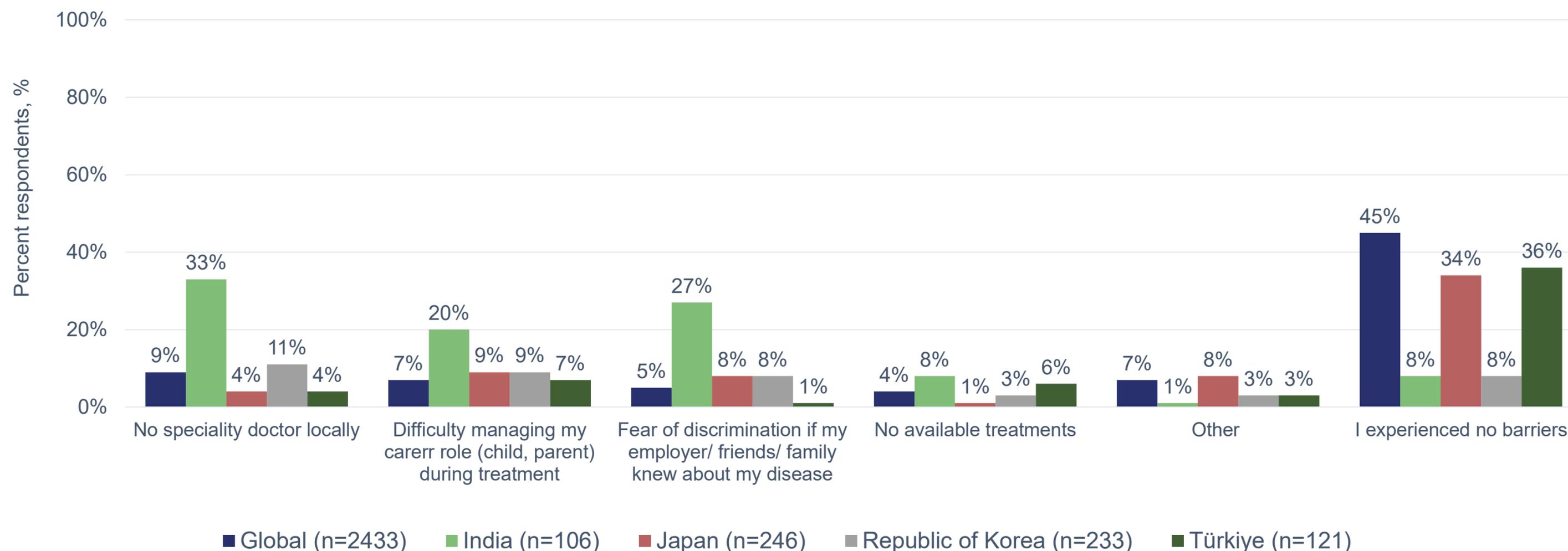


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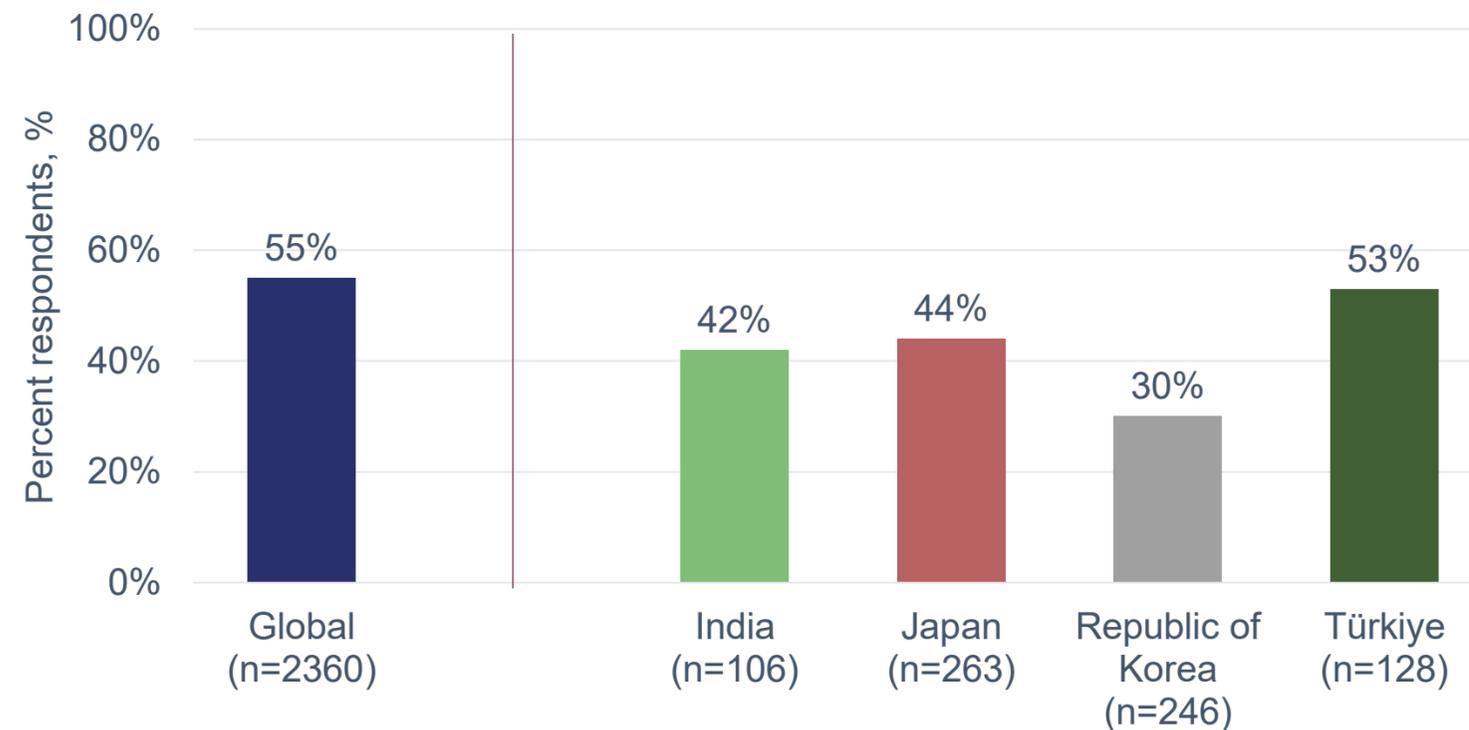
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# Involvement in SDM as Much as Desired Was Low and Varied Across Countries

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

Answer: Yes, definitely



- SDM requires open communication and partnership between the HCP and the patient
- Patient knowledge about their disease stage, subtype, prognosis, and treatment options is essential for SDM

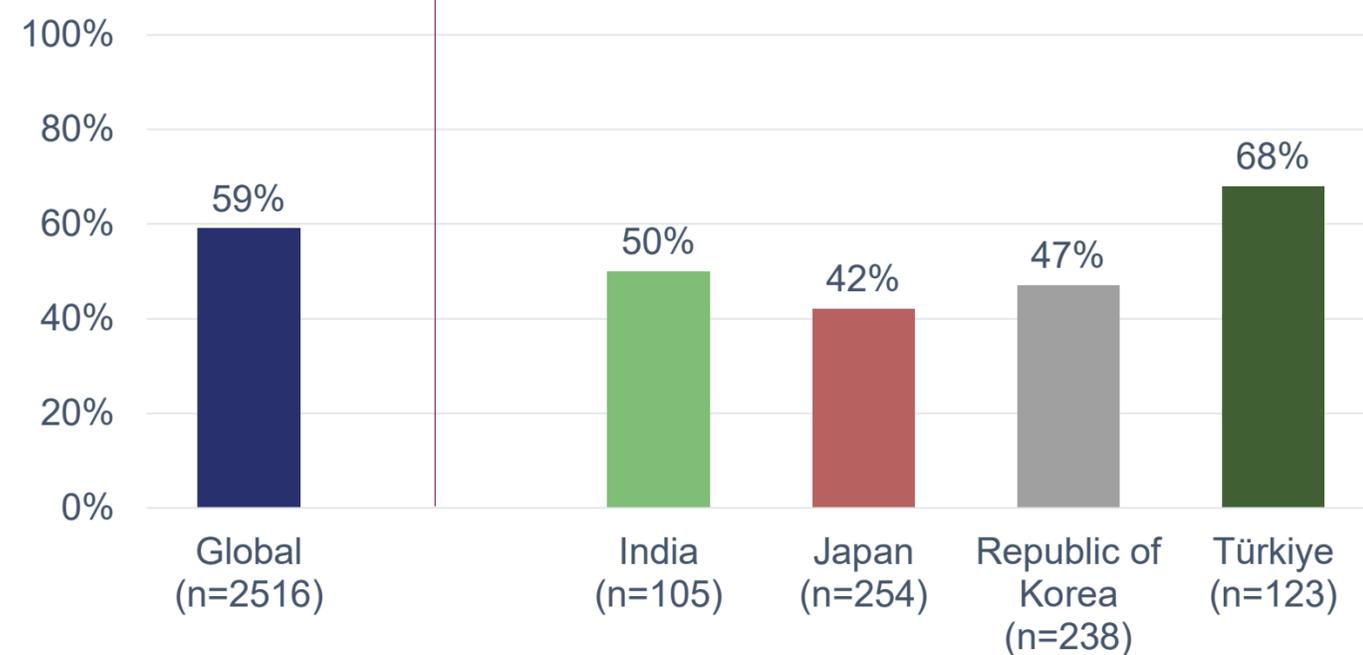
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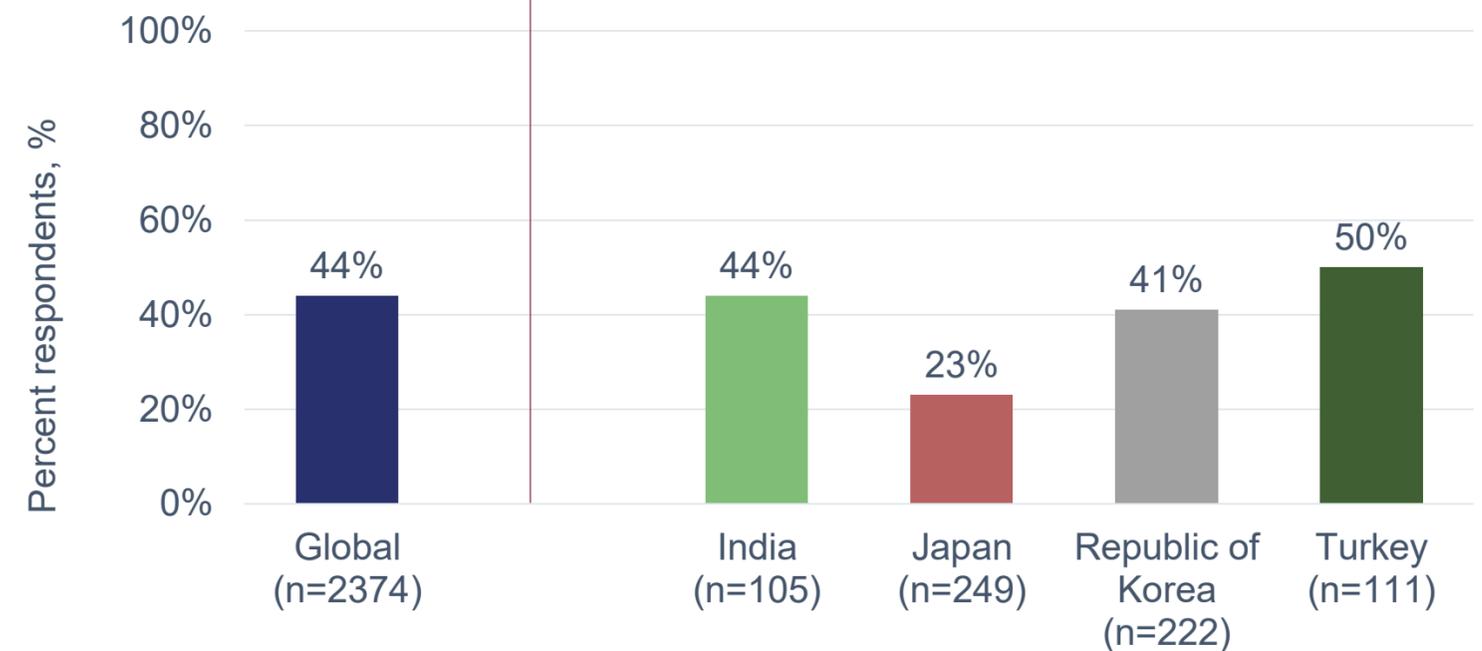
# Respondents Lacked Knowledge of Kidney Cancer Characteristics

When planning your treatments, were the following explained so you could understand?  
Answer: Yes, completely

## Stage of Cancer



## Kidney Cancer Sub-type



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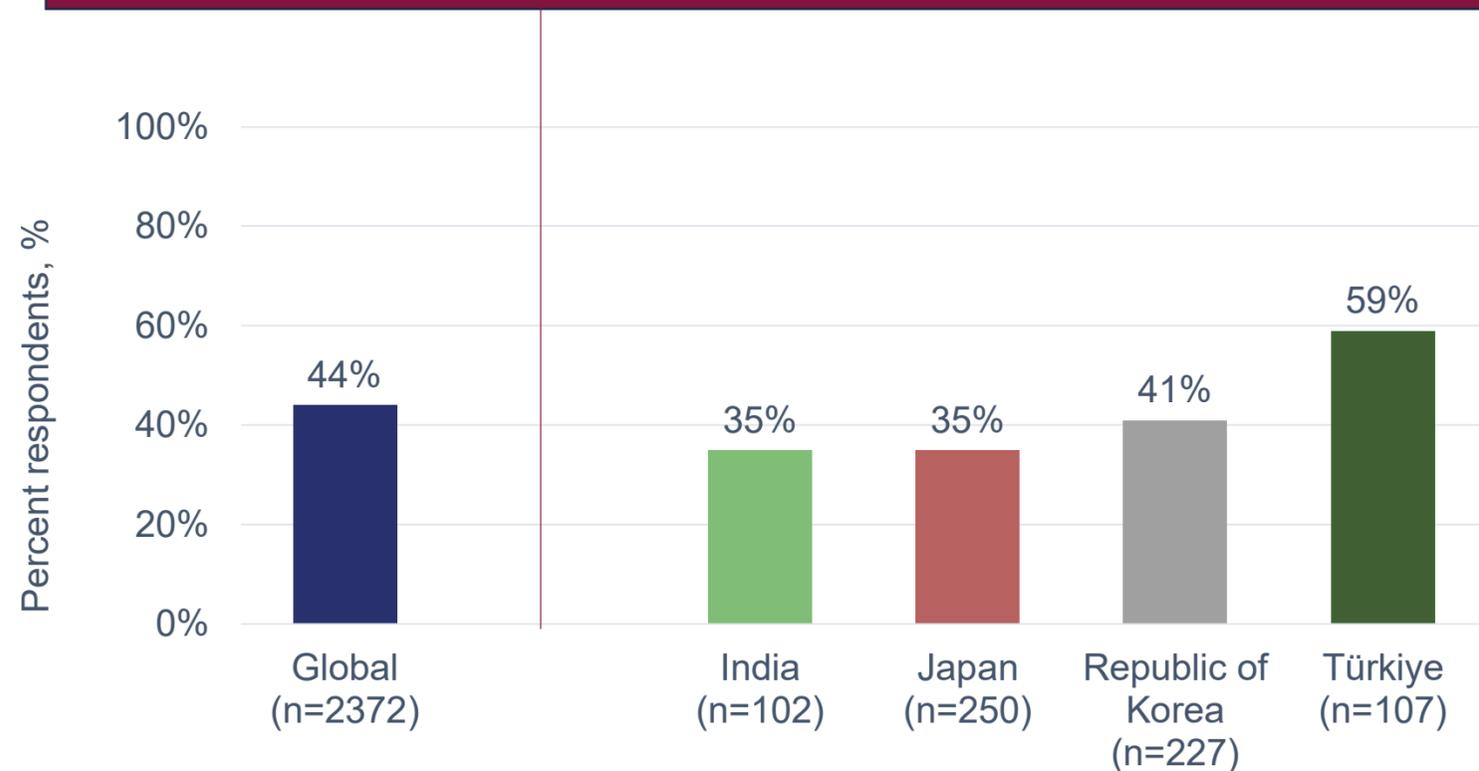
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# Respondents Lacked Knowledge About Their Prognosis

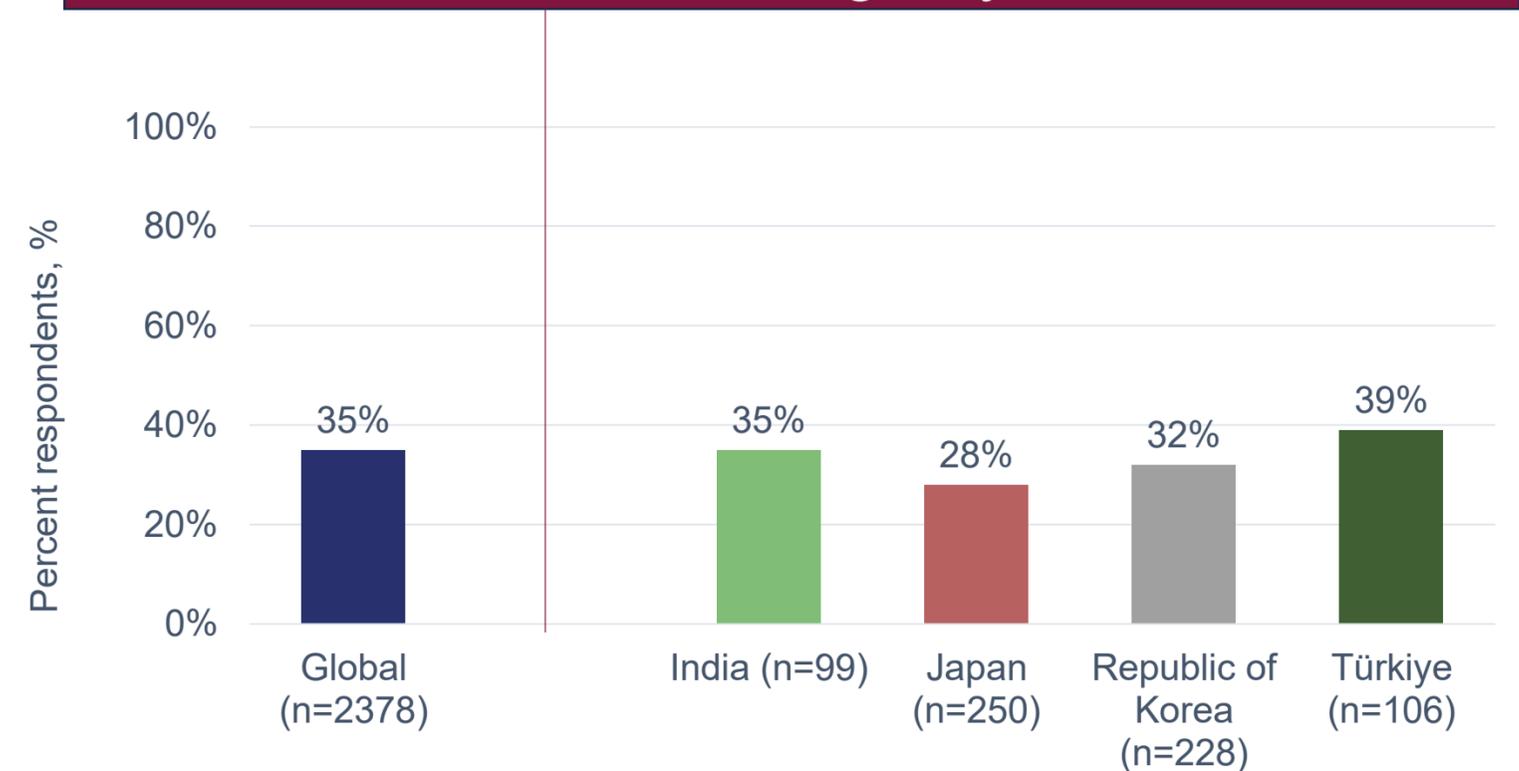
When planning your treatments, were the following explained so you could understand?

Answer: Yes, completely

### Risk of Recurrence



### Likelihood of Surviving Beyond 5 Years



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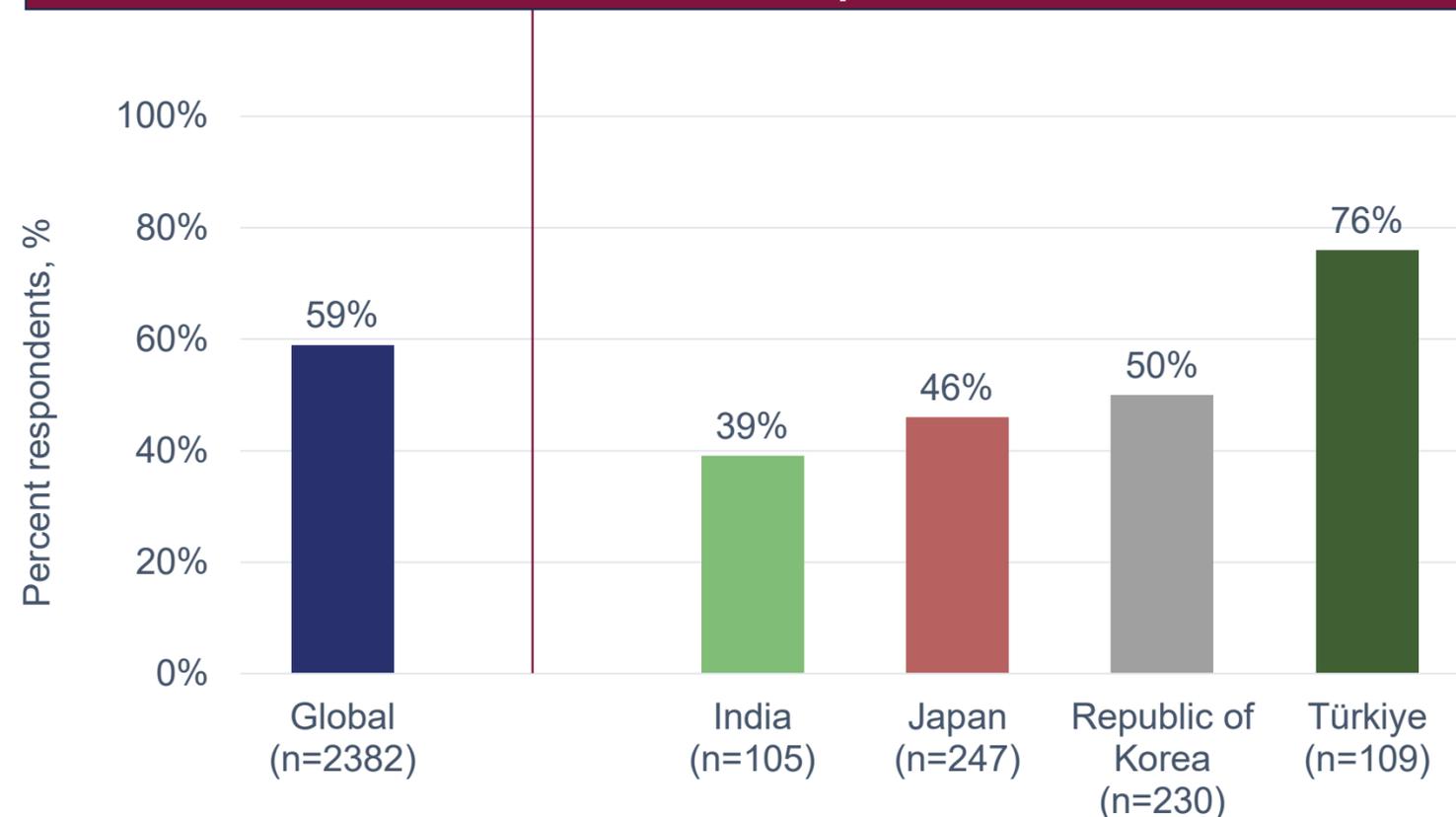
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# Respondents Lacked Knowledge of KC Treatments

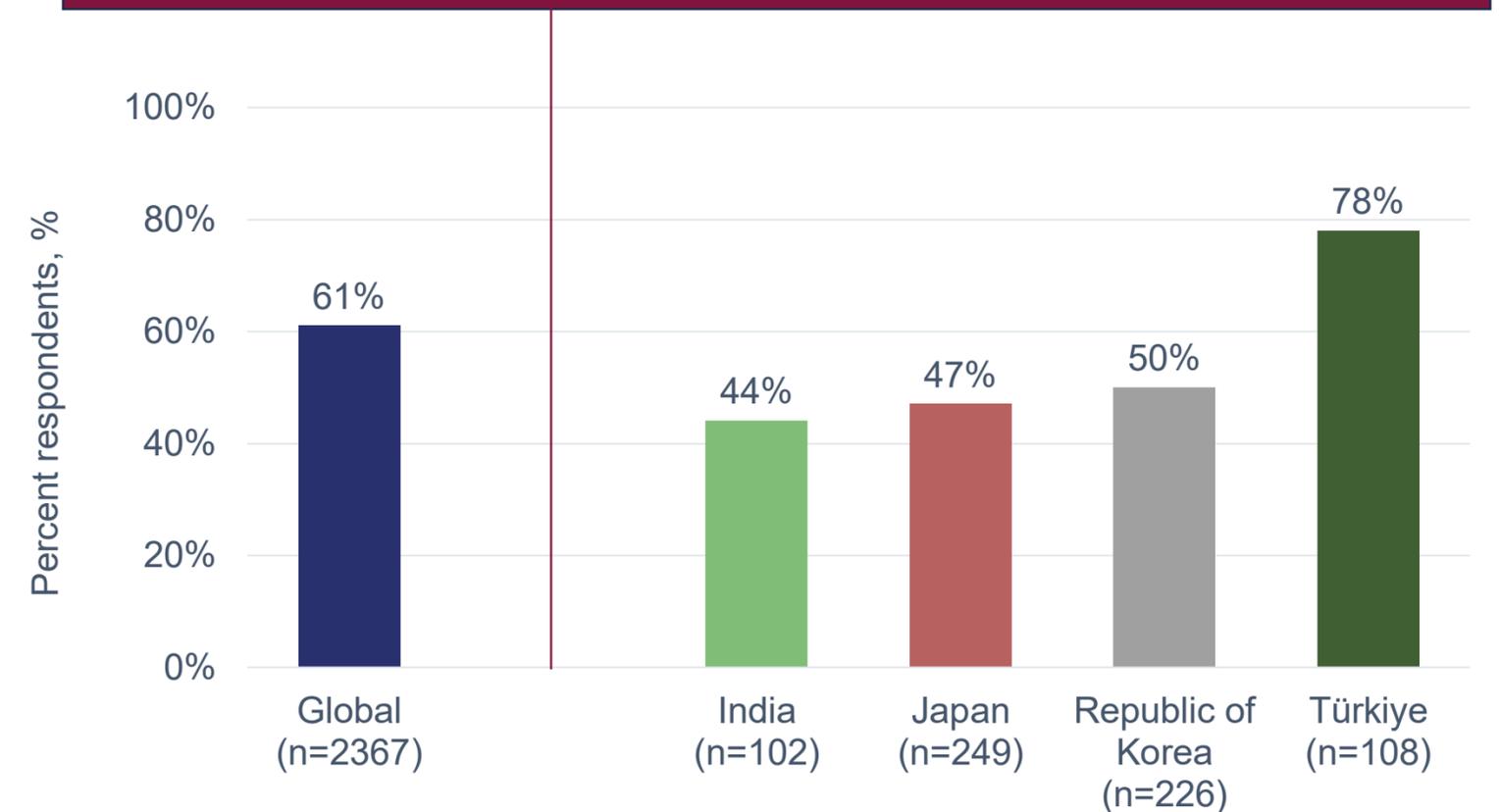
When planning your treatments, were the following explained so you could understand?

Answer: Yes, completely

### Treatment Options



### Treatment Recommendations



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# Conclusion

- Approximately 9 of 10 respondents in India and the Republic of Korea and 2 of 3 respondents in Japan and Türkiye, experience barriers to KC treatment
- Globally, 55% of respondents reported being involved in SDM; however, wide disparities remain across countries
- Most patients do not completely understand their disease, treatment options, or prognosis
- Patient experiences vary significantly by country, presenting opportunities for further investigation and best practice sharing by patient organizations and providers

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