

IKCC Global Patient Survey

Thank you for participating in this survey. By doing so, you are helping the International Kidney Cancer Coalition (IKCC) and local patient organisations gain a better understanding of the different issues that patients deal with around the world on a day-to-day basis. With this information, we will be better equipped to advocate for change to help improve the lives of kidney cancer patients everywhere. This survey is anonymous and will take 10 to 15 minutes to complete. If you wish to save your responses and return to complete your survey at a later time, you may enter your e-mail address. This e-mail will not be stored. Please see our complete Privacy and Data Security assurance at the link below. Thank you again for your participation! Please start the survey by clicking on "Continue" below.

- 1) Please describe your experience with kidney cancer
 1. I have been diagnosed with kidney cancer
 2. I am a carer or caregiver to someone who has kidney cancer

- 2) What country is the patient currently living in?

1. Australia
2. Brazil
3. Canada
4. Finland
5. France
6. Germany
7. Ghana
8. Greece
9. India
10. Japan
11. Mexico
12. Netherlands
13. Nigeria
14. Peru
15. Portugal
16. South Africa
17. South Korea
18. Spain
19. Turkey
20. United Kingdom
21. United States
- 22.
23. Other countries
24. Afghanistan
25. Åland Islands
26. Albania
27. Algeria
28. American Samoa
29. Andorra
30. Angola
31. Anguilla
32. Antarctica
33. Antigua and Barbuda
34. Argentina
35. Armenia

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36. Aruba
37. Austria
38. Azerbaijan
39. Bahamas
40. Bahrain
41. Bangladesh
42. Barbados
43. Belarus
44. Belgium
45. Belize
46. Benin
47. Bermuda
48. Bhutan
49. Bolivia
50. Bonaire, Sint Eustatius and Saba
51. Bosnia and Herzegovina
52. Botswana
53. Bouvet Island
54. British Indian Ocean Territory
55. Brunei Darussalam
56. Bulgaria
57. Burkina Faso
58. Burundi
59. Cabo Verde
60. Cambodia
61. Cameroon
62. Cayman Islands
63. Central African Republic
64. Chad
65. Chile
66. China
67. Christmas Island
68. Cocos
69. Colombia
70. Comoros
71. Congo
72. Congo
73. Cook Islands
74. Costa Rica
75. Côte d'Ivoire
76. Croatia
77. Cuba
78. Curaçao
79. Cyprus
80. Czechia
81. Denmark
82. Djibouti
83. Dominica
84. Dominican Republic
85. Ecuador
86. Egypt
87. El Salvador
88. Equatorial Guinea
89. Eritrea
90. Estonia

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91. Ethiopia
92. Falkland Islands
93. Faroe Islands
94. Fiji
95. French Guiana
96. French Polynesia
97. French Southern Territories
98. Gabon
99. Gambia
100. Georgia
101. Gibraltar
102. Greenland
103. Grenada
104. Guadeloupe
105. Guam
106. Guatemala
107. Guernsey
108. Guinea
109. Guinea-Bissau
110. Guyana
111. Haiti
112. Heard Island and McDonald Islands
113. Holy See
114. Honduras
115. Hong Kong
116. Hungary
117. Iceland
118. Indonesia
119. Iran
120. Iraq
121. Ireland
122. Isle of Man
123. Israel
124. Italy
125. Jamaica
126. Jersey
127. Jordan
128. Kazakhstan
129. Kenya
130. Kiribati
131. Kuwait
132. Kyrgyzstan
133. Lao People's Democratic Republic
134. Latvia
135. Lebanon
136. Lesotho
137. Liberia
138. Libya
139. Liechtenstein
140. Lithuania
141. Luxembourg
142. Macao
143. Macedonia
144. Madagascar
145. Malawi

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146. Malaysia
147. Maldives
148. Mali
149. Malta
150. Marshall Islands
151. Martinique
152. Mauritania
153. Mauritius
154. Mayotte
155. Micronesia
156. Moldova
157. Monaco
158. Mongolia
159. Montenegro
160. Montserrat
161. Morocco
162. Mozambique
163. Myanmar
164. Namibia
165. Nauru
166. Nepal
167. New Caledonia
168. New Zealand
169. Nicaragua
170. Niger
171. Niue
172. Norfolk Island
173. North Korea
174. Northern Mariana Islands
175. Norway
176. Oman
177. Pakistan
178. Palau
179. Palestine, State of
180. Panama
181. Papua New Guinea
182. Paraguay
183. Philippines
184. Pitcairn
185. Poland
186. Puerto Rico
187. Qatar
188. Réunion
189. Romania
190. Russian Federation
191. Rwanda
192. Saint Barthélemy
193. Saint Helena, Ascension and Tristan da Cunha
194. Saint Kitts and Nevis
195. Saint Lucia
196. Saint Martin
197. Saint Pierre and Miquelon
198. Saint Vincent and the Grenadines
199. Samoa
200. San Marino

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201. Sao Tome and Principe
202. Saudi Arabia
203. Senegal
204. Serbia
205. Seychelles
206. Sierra Leone
207. Singapore
208. Sint Maarten
209. Slovakia
210. Slovenia
211. Solomon Islands
212. Somalia
213. South Georgia and the South Sandwich Islands
214. South Sudan
215. Sri Lanka
216. Sudan
217. Suriname
218. Svalbard and Jan Mayen
219. Swaziland
220. Sweden
221. Switzerland
222. Syrian Arab Republic
223. Taiwan
224. Tajikistan
225. Tanzania, United Republic of
226. Thailand
227. Timor-Leste
228. Togo
229. Tokelau
230. Tonga
231. Trinidad and Tobago
232. Tunisia
233. Turkmenistan
234. Turks and Caicos Islands
235. Tuvalu
236. Uganda
237. Ukraine
238. United Arab Emirates
239. United States Minor Outlying Islands
240. Uruguay
241. Uzbekistan
242. Vanuatu
243. Venezuela
244. Viet Nam
245. Virgin Islands
246. Virgin Islands
247. Wallis and Futuna
248. Western Sahara
249. Yemen
250. Zambia
251. Zimbabwe

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1. England
2. Northern Ireland
3. Scotland
4. Wales

Where in the UK does the patient live?

1. England
2. Northern Ireland
3. Scotland
4. Wales

3) What is your age?

1. Under 18
2. 18-29
3. 30-45
4. 46-65
5. 66-80
6. 80+

What is the patient's age?

1. Under 18
2. 18-29
3. 30-45
4. 46-65
5. 66-80
6. 80+

4) What is your gender?

1. Male
2. Female
3. Do not wish to identify

What is the patient's gender?

1. Male
2. Female
3. Do not wish to identify

5) What sub-type of kidney cancer do you have?

1. Clear Cell Renal Cell Carcinoma
2. Papillary Renal Cell Carcinoma
3. Chromophobe Renal Cell Carcinoma
4. Unclassified Renal Cell Carcinoma

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5. XP11 Translocation Type
6. VHL
7. Renal Medullary Carcinoma
8. Collecting Duct Renal Cell Carcinoma (Bellini Duct)
9. Transitional Cell Carcinoma (Urothelial Carcinoma)
10. Renal Sarcoma (NOT Renal Cell Carcinoma with Sarcomatoid Appearance)
11. Wilms Tumour
12. Benign Tumour
13. Don't Know
14. Other _____

What sub-type of kidney cancer does the patient have?

1. Clear Cell Renal Cell Carcinoma
2. Papillary Renal Cell Carcinoma
3. Chromophobe Renal Cell Carcinoma
4. Unclassified Renal Cell Carcinoma
5. XP11 Translocation Type
6. VHL
7. Renal Medullary Carcinoma
8. Collecting Duct Renal Cell Carcinoma (Bellini Duct)
9. Transitional Cell Carcinoma (Urothelial Carcinoma)
10. Renal Sarcoma (NOT Renal Cell Carcinoma with Sarcomatoid Appearance)
11. Wilms Tumour
12. Benign Tumour
13. Don't Know
14. Other _____

6) What kind of healthcare coverage do you have? In other words, how is your kidney cancer treatment funded? (PLEASE CHOOSE ALL THAT APPLY)

1. Government healthcare
2. Private insurance
3. Self
4. Family
5. Don't know
6. Other _____

What kind of healthcare coverage does the patient have? In other words, how is their kidney cancer treatment funded? (PLEASE CHOOSE ALL THAT APPLY)

1. Government healthcare
2. Private insurance
3. Self
4. Family
5. Don't know
6. Other _____

YOUR EXPERIENCE WITH KIDNEY CANCER Now we would like to ask you some questions to learn more about your personal

THE PATIENT'S EXPERIENCE WITH KIDNEY CANCER Now we would like to ask you some questions to learn more about the patient's personal experience with kidney cancer.

7) In what year were you diagnosed?

1. Prior to 2005
2. 2005
3. 2006
4. 2007
5. 2008
6. 2009
7. 2010
8. 2011
9. 2012
10. 2013
11. 2014
12. 2015
13. 2016
14. 2017
15. 2018
16. Don't Know

In what year was the patient diagnosed?

1. Prior to 2005
2. 2005
3. 2006
4. 2007
5. 2008
6. 2009
7. 2010
8. 2011
9. 2012
10. 2013
11. 2014
12. 2015
13. 2016
14. 2017
15. 2018
16. Don't Know

8) At what stage was the kidney cancer when you were FIRST DIAGNOSED?

1. Tumour was just in the kidney without any spread (Stage 1 or Stage 2)
2. Tumour had spread locally outside of the kidney (Stage 3)
3. Tumour had spread to other organs or sites (Stage 4)
4. Don't Know

5. Other _____

At what stage was the patient's kidney cancer when they were FIRST DIAGNOSED?

1. Tumour was just in the kidney without any spread (Stage 1 or Stage 2)
2. Tumour had spread locally outside of the kidney (Stage 3)
3. Tumour had spread to other organs or sites (Stage 4)
4. Don't Know
5. Other _____

9) AFTER YOUR INITIAL DIAGNOSIS, were you told what sub-type of kidney cancer you had?

1. Yes
2. No
3. Not sure

AFTER THE PATIENT'S INITIAL DIAGNOSIS, were they told what sub-type of kidney cancer they had?

1. Yes
2. No
3. Not sure

10) AT THE TIME OF DIAGNOSIS, how well did you understand your ...

	Fully understood	Had some understanding	Had no understanding	Don't know
Stage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sub-type	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatment options	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatment recommendation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Risk of recurrence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Likelihood of survival	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

AT THE TIME OF DIAGNOSIS, how well did you understand your Stage

1. Fully understood
2. Had some understanding
3. Had no understanding
4. Don't know

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AT THE TIME OF DIAGNOSIS, how well did you understand your Sub-type

1. Fully understood
2. Had some understanding
3. Had no understanding
4. Don't know

AT THE TIME OF DIAGNOSIS, how well did you understand your Treatment options

1. Fully understood
2. Had some understanding
3. Had no understanding
4. Don't know

AT THE TIME OF DIAGNOSIS, how well did you understand your Treatment recommendation

1. Fully understood
2. Had some understanding
3. Had no understanding
4. Don't know

AT THE TIME OF DIAGNOSIS, how well did you understand your Risk of recurrence

1. Fully understood
2. Had some understanding
3. Had no understanding
4. Don't know

AT THE TIME OF DIAGNOSIS, how well did you understand your Likelihood of survival

1. Fully understood
2. Had some understanding
3. Had no understanding
4. Don't know

AT THE TIME OF DIAGNOSIS, how well did the patient understand their...

	Fully understood	Had some understanding	Had no understanding	Don't know
Stage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sub-type	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatment options	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatment recommendation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Risk of recurrence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Likelihood of survival	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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AT THE TIME OF DIAGNOSIS, how well did the patient understand their Stage

1. Fully understood
2. Had some understanding
3. Had no understanding
4. Don't know

AT THE TIME OF DIAGNOSIS, how well did the patient understand their Sub-type

1. Fully understood
2. Had some understanding
3. Had no understanding
4. Don't know

AT THE TIME OF DIAGNOSIS, how well did the patient understand their Treatment options

1. Fully understood
2. Had some understanding
3. Had no understanding
4. Don't know

AT THE TIME OF DIAGNOSIS, how well did the patient understand their Treatment recommendation

1. Fully understood
2. Had some understanding
3. Had no understanding
4. Don't know

AT THE TIME OF DIAGNOSIS, how well did the patient understand their Risk of recurrence

1. Fully understood
2. Had some understanding
3. Had no understanding
4. Don't know

AT THE TIME OF DIAGNOSIS, how well did the patient understand their Likelihood of survival

1. Fully understood
2. Had some understanding
3. Had no understanding
4. Don't know

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11) Which of the following best describes your stage of kidney cancer TODAY?

1. Kidney cancer is still only within the kidney (Stage 1 or Stage 2)
2. Kidney cancer is still locally advanced (Stage 3)
3. Kidney cancer has spread to other organs or distant sites (Stage 4)
4. I have no evidence of disease
5. I was told that I am cured
- 6.
7. Don't know
8. Other (Please Specify) _____

Which of the following best describes the patient's stage of kidney cancer TODAY?

1. Kidney cancer is still only within the kidney (Stage 1 or Stage 2)
2. Kidney cancer is still locally advanced (Stage 3)
3. Kidney cancer has spread to other organs or distant sites (Stage 4)
4. The patient has no evidence of the disease
5. The patient has been told they have been cured
6. The patient has passed away
7. Don't know
8. Other (Please Specify) _____

12) Related to your kidney cancer, how long ago was your last follow-up scan (CT, MRI, Ultrasound, or X-ray)?

1. Less than 1 year ago
2. 1-3 years ago
3. More than 3 years ago
4. Prefer not to answer
5. Don't know

Related to the patient's kidney cancer, how long ago was their last follow-up scan (CT, MRI, Ultrasound, or X-ray)?

1. Less than 1 year ago
2. 1-3 years ago
3. More than 3 years ago
4. Prefer not to answer
5. Don't know

13) From your first visit to your doctor, how long did it take for you to be CORRECTLY diagnosed with kidney cancer?

1. Less than 1 month
2. 1 – 3 months
3. 3 - 6 months
4. 6 months - 1 year
5. More than 1 year
6. Don't know

From the patient's first visit to their doctor, how long did it take for them to be CORRECTLY diagnosed with kidney cancer?

1. Less than 1 month

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2. 1 – 3 months
3. 3 - 6 months
4. 6 months - 1 year
5. More than 1 year
6. Don't know

14) How involved were you in deciding your treatment plan with your doctor?

1. I made the decision by myself
2. It was a joint decision with my doctor
3. My input was requested by my doctor
4. My doctor decided for me
5. Don't know
6. Not applicable

How involved was the patient in deciding their treatment plan with their doctor?

1. The patient made the decision on their own
2. It was a joint decision with their doctor
3. The patient's input was requested by their doctor
4. The patient's doctor decided for them
5. Don't know
6. Not applicable

15) Who or what else helped you with your treatment plan? (PLEASE CHOOSE ALL THAT APPLY)

1. My partner / spouse
2. My parents
3. My children
4. My friends /other family members
5. My local/family doctor
6. A patient organisation
7. It was my decision alone
8. My personal financial situation
9. Don't know
10. Other _____

Who or what else helped the patient with their treatment plan? (PLEASE CHOOSE ALL THAT APPLY)

1. The patient's partner / spouse
2. The patient's parents
3. The patient's children
4. The patient's friends /other family members
5. The patient's local/family doctor
6. A patient organisation
7. It was the patient's decision alone
8. The patient's personal financial situation
9. Don't know
10. Other _____

- 16) Where were you first diagnosed for your kidney cancer?
1. At my family doctor/GP's office
 2. At an emergency department
 3. At a community, local or general hospital
 4. At a major cancer centre
 5. At a major cancer centre by a doctor who specialises in kidney cancer
 6. At a private clinic
 7. Don't know
 8. Other _____

Where was the patient first diagnosed for their kidney cancer?

1. At the patient's family doctor/GP's office
2. At an emergency department
3. At a community, local or general hospital
4. At a major cancer centre
5. At a major cancer centre by a doctor who specialises in kidney cancer
6. At a private clinic
7. Don't know
8. Other _____

17) Where did you have your FIRST treatment for kidney cancer?

1. At a community, local or general hospital
2. At a major cancer centre
3. At a major cancer centre by a doctor who specialises in kidney cancer
4. At a private clinic
5. I have not had any treatment
6. Don't know
7. Other _____

Where did the patient have their FIRST treatment for kidney cancer?

1. At a community, local or general hospital
2. At a major cancer centre
3. At a major cancer centre by a doctor who specialises in kidney cancer
4. At a private clinic
5. The patient has not had any treatment
6. Don't know
7. Other _____

18) Where are you CURRENTLY being treated or followed?

1. At a community, local or general hospital
2. At a major cancer centre
3. At a major cancer centre – by a doctor who specialises in kidney cancer
4. At a private clinic
5. I am not currently being treated or followed anywhere

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6. Don't know
7. Other _____

Where is the patient CURRENTLY being treated or followed?

1. At a community, local or general hospital
2. At a major cancer centre
3. At a major cancer centre – by a doctor who specialises in kidney cancer
4. At a private clinic
5. The patient is not currently being treated or followed anywhere
6. Don't know

CLINICAL TRIALS In this part of the survey, we would like to explore your understanding of clinical trials and also determine if this was a treatment choice that was offered to you.

CLINICAL TRIALS In this part of the survey, we would like to explore the patient's understanding of clinical trials and also determine if this was a treatment choice that was offered to them.

19) Who, if anyone, has discussed clinical trials with you? (PLEASE CHOOSE ALL THAT APPLY)

1. Another patient
2. Doctor
3. Spouse, friend or family
4. Nurse
5. Patient organisation
6. Online group
7. No one
8. Don't know
9. Other _____

Who, if anyone, has discussed clinical trials with the patient? (PLEASE CHOOSE ALL THAT APPLY)

1. Another patient
2. Doctor
3. Spouse, friend or family
4. Nurse
5. Patient organisation
6. Online group
7. No one
8. Don't know
9. Other _____

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

1. Yes
2. No

3. Don't know

Has the patient ever been asked to participate in a clinical trial?

1. Yes
2. No
3. Don't know

21) When was the option of a clinical trial first discussed with you?

1. Upon diagnosis
2. After surgery
3. After I had tried other treatments
4. After I was left with no other treatment options
5. Don't know

When was the option of a clinical trial first discussed with the patient?

1. Upon diagnosis
2. After surgery
3. After the patient had tried other treatments
4. After the patient was left with no other treatment options
5. Don't know

22) At that point, how well did you understand the risks and benefits of participating in a clinical trial?

1. Very well
2. I had some understanding
3. I had a very limited understanding
4. Don't know

At that point, how well did the patient understand the risks and benefits of participating in a clinical trial?

1. Very well
2. The patient had some understanding
3. The patient had a very limited understanding
4. Don't know

23) Did you agree to participate in the clinical trial?

1. Yes
2. No
3. Don't know

Did the patient agree to participate in the clinical trial?

1. Yes

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2. No
3. Don't know

24) Why did you agree to participate? (PLEASE CHOOSE ALL THAT APPLY)

1. My doctor recommended it
2. I thought it might offer better care
3. I wanted a specific type of treatment
4. It was my only option for treatment
5. I wanted to help kidney cancer research
6. Affordability, financial reasons
7. Don't know

Why did the patient agree to participate? (PLEASE CHOOSE ALL THAT APPLY)

1. The patient's doctor recommended it
2. The patient thought it might offer better care
3. The patient wanted a specific type of treatment
4. It was the patient's only option for treatment
5. The patient wanted to help kidney cancer research
6. Affordability, financial reasons
7. Don't know

25) How satisfied were you overall with your clinical trial experience?

1. Very satisfied
2. Satisfied
3. Very dissatisfied
4. Don't know

How satisfied was the patient overall with their clinical trial experience?

1. Very satisfied
2. Satisfied
3. Very dissatisfied
4. Don't know

26) If asked, how likely is it that you would agree to participate in a clinical trial?

1. Likely
2. Maybe; would need more information
3. Not likely
4. Don't know

If asked, how likely is it that the patient would agree to participate in a clinical trial?

1. Likely
2. Maybe; the patient would need more information

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3. Not likely
4. Don't know

27) What are the reasons for not wanting to participate? (PLEASE CHOOSE ALL THAT APPLY)

1. Lack of enough information to make a decision
2. Not eligible for the trial
3. Distrust of clinical trials
4. Fear of placebo
5. Fear of uncertainty
6. Extra tests or interventions required
7. Geographic distance
8. Affordability, financial costs
9. Not available at my hospital
10. Toxicity of the treatment
11. Don't know
12. Other _____

What are the reasons for the patient not wanting to participate? (PLEASE CHOOSE ALL THAT APPLY)

1. Lack of enough information to make a decision
2. Not eligible for the trial
3. Distrust of clinical trials
4. Fear of placebo
5. Fear of uncertainty
6. Extra tests or interventions required
7. Geographic distance
8. Affordability, financial costs
9. Not available at my hospital
10. Toxicity of the treatment
11. Don't know
12. Other _____

QUALITY OF LIFE Please help us to understand your experience with kidney cancer so we can provide assistance when and where it is most needed.

QUALITY OF LIFE Please help us to understand the patient's experience with kidney cancer so we can provide assistance when and where it is most needed.

28) Which of the following issues have impacted your sense of emotional well being since your diagnosis? (PLEASE CHOOSE ALL THAT APPLY)

1. General anxiety
2. Disease-related anxiety
3. Fear of dying
4. Fear of the cancer coming back (recurrence)
5. Depression

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6. Isolation
7. Changes in relationships with loved ones, friends or co-workers
8. Difficulty on the job or in school
9. Stress related to financial issues
10. Loss/reduction in employment
11. Difficulty navigating the healthcare system
12. Problems getting health or life insurance coverage
13. Concerns about body image/changes in physical appearance
14. Relationships with friends, others
15. Sexuality
16. None
17. Other _____

Which of the following issues have impacted the patient's sense of emotional well being since their diagnosis? (PLEASE CHOOSE ALL THAT APPLY)

1. General anxiety
2. Disease-related anxiety
3. Fear of dying
4. Fear of the cancer coming back (recurrence)
5. Depression
6. Isolation
7. Changes in relationships with loved ones, friends or co-workers
8. Difficulty on the job or in school
9. Stress related to financial issues
10. Loss/reduction in employment
11. Difficulty navigating the healthcare system
12. Problems getting health or life insurance coverage
13. Concerns about body image/changes in physical appearance
14. Relationships with friends, others
15. Sexuality
16. None
17. Other _____

29) Have you ever communicated any of these emotional issues arising from your kidney cancer to your doctor or to any other healthcare professional?

1. Yes
2. No
3. Don't know

Has the patient ever communicated any of these emotional issues arising from their kidney cancer to their doctor or to any other healthcare professional?

1. Yes
2. No
3. Don't know

30) Looking back, what have been the three most difficult times for you personally during your experience with kidney cancer?

(PLEASE CHOOSE UP TO THREE RESPONSES)

1. During the process of diagnosis
2. Surveillance (or “watchful waiting”) period
3. Surgery & recovery afterwards
4. Follow up scans
5. Waiting for surgery or scan results
6. Diagnosis of recurrence
7. Treatment for recurrence
8. Diagnosis of further disease progression
9. Dealing with side effects of treatment
10. Transition to palliative care
11. Long term adjustment, survivorship
12. None
13. Other _____

Looking back, what have been the three most difficult times for the patient personally during their experience with kidney cancer?

(PLEASE CHOOSE UP TO THREE RESPONSES)

1. During the process of diagnosis
2. Surveillance (or “watchful waiting”) period
3. Surgery & recovery afterwards
4. Follow up scans
5. Waiting for surgery or scan results
6. Diagnosis of recurrence
7. Treatment for recurrence
8. Diagnosis of further disease progression
9. Dealing with side effects of treatment
10. Transition to palliative care
11. Long term adjustment, survivorship
12. None
13. Other _____

31) Which of the following conditions have impacted your sense of physical well being since your diagnosis? (PLEASE CHOOSE ALL THAT APPLY)

1. Fatigue
2. Trouble concentrating
3. Mucositis/mouth ulcers
4. Muscle weakness
5. Pain related to surgery
6. Bowel changes
7. Loss of appetite
8. Changes in taste and smell
9. Sleeplessness
10. Itching
11. Hair loss
12. Change of hair colour
13. Memory loss
14. Changes in sexual function
15. Aching joints
16. Sore feet and hands

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17. Weight loss
18. Cramps
19. Fluid retention
20. Skin reactions
21. Nausea and vomiting
22. None
23. Other _____

Which of the following conditions have impacted the patient's sense of physical well being since their diagnosis? (PLEASE CHOOSE ALL THAT APPLY)

1. Fatigue
2. Trouble concentrating
3. Mucositis/mouth ulcers
4. Muscle weakness
5. Pain related to surgery
6. Bowel changes
7. Loss of appetite
8. Changes in taste and smell
9. Sleeplessness
10. Itching
11. Hair loss
12. Change of hair colour
13. Memory loss
14. Changes in sexual function
15. Aching joints
16. Sore feet and hands
17. Weight loss
18. Cramps
19. Fluid retention
20. Skin reactions
21. Nausea and vomiting
22. None
23. Other _____

32) How open would you say you have been in communicating these issues with your doctor or other healthcare professional?

1. I have been very open and told the doctor or other health professional everything in great detail
2. I have told the doctor about some of my issues, but not all of them or to the full extent
3. I have held back some details and minimized my symptoms and side effects
4. I have chosen not to communicate these issues at all
5. I have not had the opportunity to communicate these issues
6. Don't know

How open would you say the patient has been in communicating these issues with their doctor or other healthcare professional?

1. The patient has been very open and told the doctor or other health professional everything in great detail
2. The patient has told the doctor about some of their issues, but not all of them or to the full extent
3. The patient has held back some details and minimized their symptoms and side effects

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4. The patient has chosen not to communicate these issues at all
5. The patient has not had the opportunity to communicate these issues
6. Don't know

33) How helpful was the doctor or healthcare team to you?

1. Very helpful
2. Somewhat helpful
3. Not helpful at all
4. Don't know

How helpful was the doctor or healthcare team to the patient?

1. Very helpful
2. Somewhat helpful
3. Not helpful at all
4. Don't know

34) Which barriers (if any) have you experienced in receiving quality treatment for your kidney cancer? (PLEASE CHOOSE ALL THAT APPLY)

1. Lack of affordability, cost of treatment
2. Lack of access to treatment centre/prohibitive travel
3. Language/inability to understand the treatment
4. Lack of access to the most up-to-date treatment or equipment
5. Wait time to treatment was longer than necessary
6. Lack of personal support
7. No speciality doctor locally
8. Difficulty managing my carer/caregiver role (child, parent, disabled person) while in treatment
9. Fear of discrimination if my employer/friends/family knew about my disease
10. No available treatments
11. None
12. Other barrier not mentioned above _____

Which barriers (if any) has the patient experienced in receiving quality treatment for their kidney cancer? (PLEASE CHOOSE ALL THAT APPLY)

1. Lack of affordability, cost of treatment
2. Lack of access to treatment centre/prohibitive travel
3. Language/inability to understand the treatment
4. Lack of access to the most up-to-date treatment or equipment
5. Wait time to treatment was longer than necessary
6. Lack of personal support
7. No speciality doctor locally
8. Difficulty managing the patient's carer/caregiver role (child, parent, disabled person) while in treatment
9. Fear of discrimination if the patient's employer/friends/family knew about their disease
10. No available treatments
11. None
12. Other barrier not mentioned above _____

35) Have you ever used the services of a patient support group to help you with your kidney cancer?

1. Yes
2. No
3. Don't know

Has the patient ever used the services of a patient support group to help them with their kidney cancer?

1. Yes
2. No
3. Don't know

36) How helpful has the patient support group been in providing you with the information and support you have needed?

1. Helpful on many issues
2. Helpful on a few issues
3. Not helpful at all
4. Don't know

How helpful has the patient support group been in providing the patient with the information and support they have needed?

1. Helpful on many issues
2. Helpful on a few issues
3. Not helpful at all
4. Don't know

37) How helpful has each of the patient support group services been to you in providing... (PLEASE SPECIFY FOR EACH SERVICE)

	Helpful	Not Helpful	Not applicable
Information about kidney cancer treatment options	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Websites, social media and online forums for discussion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Telephone support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Navigation within healthcare system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient support group meetings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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treatment options

1. Helpful
2. Not Helpful
3. Not Applicable

How helpful has each of the patient support group services been to you in providing Websites, social media and online forums for discussion

1. Helpful
2. Not Helpful
3. Not Applicable

How helpful has each of the patient support group services been to you in providing Telephone support

1. Helpful
2. Not Helpful
3. Not Applicable

How helpful has each of the patient support group services been to you in providing Navigation within healthcare system

1. Helpful
2. Not Helpful
3. Not Applicable

How helpful has each of the patient support group services been to you in providing Financial assistance

1. Helpful
2. Not Helpful
3. Not Applicable

How helpful has each of the patient support group services been to you in providing Emotional support

1. Helpful
2. Not Helpful
3. Not Applicable

How helpful has each of the patient support group services been to you in providing Patient support group meetings

1. Helpful
2. Not Helpful
3. Not Applicable

How helpful has each of the patient support group services been to the patient in providing... (PLEASE SPECIFY FOR EACH SERVICE)

	Helpful	Not Helpful	Not applicable
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Information about kidney cancer treatment options	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Websites, social media and online forums for discussion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Telephone support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Navigation within healthcare system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient support group meetings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How helpful have the patient support group services been to the patient in providing Information about kidney cancer treatment options

1. Helpful
2. Not Helpful
3. Not Applicable

How helpful have the patient support group services been to the patient in providing Websites, social media and online forums for discussion

1. Helpful
2. Not Helpful
3. Not Applicable

How helpful have the patient support group services been to the patient in providing Telephone support

1. Helpful
2. Not Helpful
3. Not Applicable

How helpful have the patient support group services been to the patient in providing Navigation within healthcare system

1. Helpful
2. Not Helpful
3. Not Applicable

How helpful have the patient support group services been to the patient in providing Financial assistance

1. Helpful
2. Not Helpful
3. Not Applicable

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How helpful have the patient support group services been to the patient in providing Emotional support

1. Helpful
2. Not Helpful
3. Not Applicable

How helpful have the patient support group services been to the patient in providing Patient support group meetings

1. Helpful
2. Not Helpful
3. Not Applicable

38) Overall how much understanding would you say you have about each of the following?

	A full understanding	Some understanding	No understanding	Don't know
Biopsies for kidney cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Surgical options	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Immunotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Targeted therapies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Radiation therapies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ablative therapies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Palliative care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Active surveillance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutrition/lifestyle	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complementary therapies (e.g. meditation, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Guidelines for kidney cancer care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Guidelines for kidney cancer follow up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall how much understanding would you say you have about Biopsies for kidney cancer?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

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Overall how much understanding would you say you have about Surgical options?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say you have about Immunotherapy?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say you have about Targeted therapies?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say you have about Radiation therapies?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say you have about Ablative therapies?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say you have about Palliative care?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say you have about Active surveillance?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say you have about Nutrition/lifestyle?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say you have about Complementary therapies (e.g. meditation, etc.)?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say you have about Guidelines for kidney cancer care?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say you have about Guidelines for kidney cancer follow up?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say the patient has about each of the following?

	A full understanding	Some understanding	No understanding	Don't know
Biopsies for kidney cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Surgical options	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Immunotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Targeted therapies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Radiation therapies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ablative therapies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Palliative care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Active surveillance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Nutrition/lifestyle	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complementary therapies (e.g. meditation, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Guidelines for kidney cancer care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Guidelines for kidney cancer follow up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall how much understanding would you say the patient has about Biopsies for kidney cancer?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say the patient has about Surgical options?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say the patient has about Immunotherapy?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say the patient has about Targeted therapies?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say the patient has about Radiation therapies?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say the patient has about Ablative therapies?

1. A full understanding
2. Some understanding

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3. No understanding
4. Don't know

Overall how much understanding would you say the patient has about Palliative care?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say the patient has about Active surveillance?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say the patient has about Nutrition/lifestyle?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say the patient has about Complementary therapies (e.g. meditation, etc.)?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say the patient has about Guidelines for kidney cancer care?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

Overall how much understanding would you say the patient has about Guidelines for kidney cancer follow up?

1. A full understanding
2. Some understanding
3. No understanding
4. Don't know

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by country (where sample permits) will be shared on our website www.ikcc.org As a global community, we want to bring attention to kidney cancer and the needs of the kidney cancer patient. We appreciate that you took the time to be a part of this. For patient support in your country, please visit a list of participating organisations on our website: www.ikcc.org **THANK YOU!**