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Foreword

Kidney cancer is a global issue. Every year, an estimated 431,000 people worldwide are diagnosed with the disease. The diagnosis of kidney cancer and other renal masses is on the rise globally and presents an increasing burden on health systems, governments, and most of all to individual patients and their families. Although therapies have improved for both early-stage and late-stage Renal Cell Carcinoma (RCC) patients, little is known about the variances in patient experience from country to country, including unmet needs and best practices in patient education, quality of life, and involvement in clinical trials and registries.

To improve collective understanding, the International Kidney Cancer Coalition (IKCC) has partnered with Affiliate Organisations to establish a biennial global survey, which launched in 2018. This programme invites the organisation’s affiliates and members to contribute to the collection of feedback on patient experience. The results are used to ensure that patients’ voices are heard and to drive planning and sharing of best practice.

In 2020, the IKCC appointed Picker to administer this programme, including updating the patient questionnaire, with the intention to further explore and benchmark worldwide patient experience. This partnership continued for the 2022 survey iteration.

The survey was published online in 16 languages and promoted through IKCC affiliates and partners, as well as via the IKCC social media and web pages, between September and November 2022. The survey achieved 2213 patient and carer/caregiver responses across 39 countries globally.

This report presents the data from India.
India Key Findings Summary

Genetic testing

38% of patients reported they met the criteria for genetic testing (diagnosed under 46 years old; family history of kidney cancer or bilateral disease) but were not offered genetic testing (Q36).

2% reported they had some of the relevant risk factors (diagnosed under 46 years old; family history of kidney cancer or bilateral disease) and were either offered genetic testing or genetic testing had been completed at time of survey (Q36).

Patient feedback on management of small renal mass

If diagnosed with a small renal mass, 50% reported they would be willing to participate in Active Surveillance with regular imaging such as ultrasound and CT scans if their doctor recommended it (Q20).

52% of respondents would be willing to have a biopsy of a small renal growth if it might change the treatment decision (Q21).

Surveillance preferences

Following surgery for kidney cancer or kidney growth (Q22):

58% would prefer to have regular imaging scans for less than 2 years

33% would prefer between 2 and 6 years

0% preferred more than 6 years

2% would make this decision based on their healthcare team’s opinion.
India Key Findings Summary

Shared decision-making

46% of respondents reported that they were definitely involved as much as they wanted to be in developing their treatment plan (Q13+)

Understanding of diagnosis and treatment options

50% of respondents completely understood treatment options when planning their treatments (Q11_3+)

44% felt that treatment recommendations were completely understood when planning their treatments (Q11_4+)

9% reported that the likelihood of surviving their cancer beyond five years was not explained when planning their treatments (Q11_6+)

Understanding of medical care and treatment

22% of respondents reported they did not understand adjuvant therapy (treatment aimed at reducing the chance of recurrence after surgery) (Q18_7+)

Emotional wellbeing

34% felt their sense of emotional well-being since their diagnosis has always been impacted by disease-related anxiety (Q24_2)

41% reported fear of the cancer/growth coming back (recurrence) always impacts their sense of emotional well-being since their diagnosis (Q24_4)

38% reported always feeling their sense of emotional well-being since their diagnosis being impacted by sadness or depression (Q24_5)

Please note questions marked with a ‘+’ indicate a derived question, for more information on how these are calculated, see derived questions in the methodology section
India Key Findings Summary

Support from healthcare professionals

57% of respondents reported their doctor or healthcare professional was very helpful when they spoke about their concerns (Q27+)

Clinical trials

62% of respondents reported they had been asked by a health professional to consider participating in a cancer clinical trial (Q30)

19% agreed to participate in the cancer clinical trial (Q31)

100% reported they were very satisfied or satisfied with their overall experience of the cancer clinical trial (Q33)

Please note questions marked with a ‘+’ indicate a derived question, for more information on how these are calculated, see derived questions in the methodology section
Methodology

Survey fieldwork

The survey was hosted on the third-party online survey portal Qualtrics. It was administered through an open link and distributed by IKCC global affiliates to patients with kidney cancer or a kidney growth and their caregivers.

The survey was available between 26 September 2022 and 21 November 2022. It was promoted at regular intervals by the IKCC global affiliates and partners, as well as advertised via the IKCC and partner organisation’s social media and websites.

Analysis and reporting

Comparison to global data in this report refers to the 2213 patient and carer/caregiver responses across 39 countries globally.

Please note that there are differences in kidney cancer care provision between countries, as well as differences in the profile of respondents globally. Within each country, respondents were recruited by patient organisations serving different patient populations at varying stages of disease. Therefore, variations in findings across countries may reflect bias in how respondents were accrued. Moreover, method of survey completion differed by country of residence, with some countries primarily conducting interviewer-led surveys, while patients in other countries primarily completed the survey independently. Several cultural differences are expected to be found within the survey findings, such as willingness to disclose information on certain topics. For these reasons, caution should be taken when comparing subgroup results to global data.

Questionnaire routing

To improve respondent experience, routed questions were used in the survey tool to ensure respondents were only shown questions that were relevant to them. For example: Q30: “Have you ever been asked by a health professional to consider participating in a cancer clinical trial?”. Only respondents that answered “Yes” to this question, were directed to Q31: “Did you agree to participate in the cancer clinical trial?”. Consequently, some questions were only asked of a subset of respondents. Furthermore, respondents had the ability to leave questions blank. This means that the total number of respondents may fluctuate between questions. Where applicable the total number of respondents, or base size, is indicated with the abbreviation n.
**Derived questions**

Some questions were not applicable to all respondents but were not preceded by a filter/routing question. These questions have response options such as “I did not need” or “Don’t know / Can’t remember”. Overall percentages were calculated after removing these non applicable respondents – see example below. This ensures that the reported data remains focussed on those respondents to whom the question applied or who could recall the details. These questions are indicated using a plus (+) symbol, e.g., Q8 becomes Q8+.

**Data presentation**

Throughout this report, percentages have been rounded to 0 decimal places. This means that sometimes the total for a single-response question can be just below or just above 100%.

**Further analysis**

Significance testing and benchmarking of results have been introduced into analysis for 2022 data. More information about interpretation and presentation of this data can be found in the detailed analysis of country data and comparisons to global findings sections.

For further information on methodology, please see Appendix 2.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q8</td>
<td>852</td>
<td>909</td>
<td>243</td>
<td>1,994</td>
</tr>
<tr>
<td>Q8+</td>
<td>852</td>
<td>909</td>
<td>243</td>
<td>1,751</td>
</tr>
</tbody>
</table>

Q8 - WHEN YOU WERE FIRST DIAGNOSED, were you told what subtype of kidney cancer or kidney growth you had?

Q8+ - WHEN YOU WERE FIRST DIAGNOSED, were you told what subtype of kidney cancer or kidney growth you had?
India Participant characteristics

This report outlines the results from the 107 respondents from India. Comprised of (Q1):

- 87 patients
- 20 carers or caregivers
- 0 undisclosed

Age (Q4/Q6, n=105)

- <18: 0%
- 18-29: 6%
- 30-45: 43%
- 46-65: 48%
- 66-80: 4%
- 80+: 0%

Gender (Q5, n=107)

- 61% male
- 35% female
- 2% Prefer to self describe
- 3% Do not wish to identify

Year of diagnosis (Q6, n=105)

- Prior to 2008: 24%
- 2008-2010: 1%
- 2011-2013: 2%
- 2014-2016: 3%
- 2017-2019: 20%
- 2020-Present: 50%

Current stage of cancer (Q16 coded, n=104)

- Localised: 42%
- Advanced / metastatic: 8%
- No evidence / cured: 50%

Cancer subtype (Q2, n=107)

- Clear Cell Renal Cell Carcinoma: 57%
- Papillary Renal Cell Carcinoma: 27%
- Chromophobe Renal Cell Carcinoma: 8%
- Unclassified Renal Cell Carcinoma: 4%
- Xp11 Translocation Type: 0%
- VHL (Von Hippel-Lindau syndrome): 0%
- I was not told: 0%
- Don’t know / Can’t remember: 0%
- Other: 4%
Results: Diagnosis

The data presented in this section are from questions that asked about diagnosis.

58% (n=55) were told what sub-type of kidney cancer or kidney growth they had when they were first diagnosed, compared to 36% globally (n=717) (Figure 2; Q8+).

**Figure 1. Q6 - In what year were you diagnosed?**

<table>
<thead>
<tr>
<th>Year Range</th>
<th>India (n=105)</th>
<th>Global (n=2110)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prior to 2008</td>
<td>24%</td>
<td>11%</td>
</tr>
<tr>
<td>2008-2010</td>
<td>1%</td>
<td>6%</td>
</tr>
<tr>
<td>2011-2013</td>
<td>2%</td>
<td>7%</td>
</tr>
<tr>
<td>2014-2016</td>
<td>3%</td>
<td>13%</td>
</tr>
<tr>
<td>2017-2019</td>
<td>20%</td>
<td>24%</td>
</tr>
<tr>
<td>2020-Present</td>
<td>39%</td>
<td>50%</td>
</tr>
</tbody>
</table>

**Subtype of kidney tumour(s) at diagnosis**

**Figure 2. Q8+ - WHEN YOU WERE FIRST DIAGNOSED, were you told what sub-type of kidney cancer or kidney growth you had?**

<table>
<thead>
<tr>
<th></th>
<th>India (n=95)</th>
<th>Global (n=1979)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>58%</td>
<td>36%</td>
</tr>
<tr>
<td>No</td>
<td>42%</td>
<td>64%</td>
</tr>
</tbody>
</table>
Globally, respondents were most likely to be first diagnosed at a community, local or general hospital (35%, n=775) (Figure 3: Q7).

In India, respondents were most likely to be first diagnosed at a community, local or general hospital (38%, n=41).

**Figure 3. Q7 - Where was your kidney cancer or kidney growth FIRST DIAGNOSED?**

- **India (n=107) Global (n=2200)**
  - At my family doctor’s office: 21% (India), 17% (Global)
  - At an emergency department: 11% (India), 15% (Global)
  - At a community, local or general hospital: 38% (India), 35% (Global)
  - At a major cancer centre: 5% (India), 5% (Global)
  - At a major cancer centre by a doctor who specialises in kidney cancer: 6% (India), 5% (Global)
  - At a private clinic: 5% (India), 10% (Global)
  - Don’t know / Can’t remember: 1% (India), 1% (Global)
  - Other: 0% (India), 11% (Global)
Results: Diagnosis

Stage of kidney tumour(s) at diagnosis

At diagnosis (Figure 4: Q9):

- **53%** (n=56) of respondents were at stage 1A
- **37%** (n=39) were at stage 2
- **4%** (n=4) were at stage 3
- **4%** (n=4) were at stage 4
- **3%** (n=3) were not told what stage their kidney tumour was at diagnosis

**Figure 4. Q9 - At what stage was the kidney tumour when you were FIRST DIAGNOSED?**

<table>
<thead>
<tr>
<th>Stage Description</th>
<th>India (n=106)</th>
<th>Global (n=2204)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tumour was less than 4 cm (1.6 inches) and was just in the kidney without any spread (Stage 1A)</td>
<td>53%</td>
<td>19%</td>
</tr>
<tr>
<td>Tumour was larger than 4cm (1.6inches) and was just in the kidney without any spread (Stage 1B or Stage 2)</td>
<td>37%</td>
<td>36%</td>
</tr>
<tr>
<td>Tumour had spread locally outside of the kidney (Stage 3)</td>
<td>4%</td>
<td>16%</td>
</tr>
<tr>
<td>Tumour had spread to other organs or sites (Stage 4)</td>
<td>4%</td>
<td>19%</td>
</tr>
<tr>
<td>I was not told</td>
<td>3%</td>
<td>4%</td>
</tr>
<tr>
<td>Don’t know / Can’t remember</td>
<td>0%</td>
<td>2%</td>
</tr>
<tr>
<td>Other</td>
<td>0%</td>
<td>2%</td>
</tr>
</tbody>
</table>
Results: Diagnosis

Time to correct diagnosis

90% of respondents (n=95) reported that it was less than 3 months between their first thinking that there might be something wrong to when they were correctly diagnosed, relative to 71% globally (n=1407) (Figure 5; Q10+).

Figure 5. Q10+ - How long was it from the time you first thought something might be wrong with you to being diagnosed?

<table>
<thead>
<tr>
<th>Time Interval</th>
<th>India (n=106)</th>
<th>Global (n=1968)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 1 month</td>
<td>50%</td>
<td>44%</td>
</tr>
<tr>
<td>1 – 3 months</td>
<td>40%</td>
<td>28%</td>
</tr>
<tr>
<td>3 - 6 months</td>
<td>9%</td>
<td>14%</td>
</tr>
<tr>
<td>6 months - 12 months</td>
<td>1%</td>
<td>8%</td>
</tr>
<tr>
<td>More than 12 months</td>
<td>0%</td>
<td>7%</td>
</tr>
</tbody>
</table>
Results: Diagnosis

Knowledge when planning treatments

When planning their treatments, respondents in India were most likely to report Treatment options (50%, n=53) was completely explained in a way they could understand (Figure 9; Q11_3+). This is in contrast to Likelihood of surviving your cancer beyond five years (25%, n=26) which respondents were least likely to report as being completely explained in a way they could understand (Figure 12; Q11_6+).

Figure 7. Q11_1+ – When planning your treatments, were the following explained in a way you could understand? – Stage of cancer

![Bar chart showing comparison between India and Global for stage of cancer understanding.](chart1)

Figure 8. Q11_2+ – When planning your treatments, were the following explained in a way you could understand? – Sub-type of cancer

![Bar chart showing comparison between India and Global for sub-type of cancer understanding.](chart2)
Results: Diagnosis

Figure 9. Q11.3+ – When planning your treatments, were the following explained in a way you could understand? – Treatment options

![Bar chart showing the percentage of patients who understood treatment options in India and globally.](chart1)

India (n=106) | Global (n=2001)  
--- | ---  
Yes, completely | 50% | 54%  
Yes, to some extent | 46% | 35%  
No, this was not explained | 4% | 11%  

Figure 10. Q11.4+ – When planning your treatments, were the following explained in a way you could understand? – Treatment recommendations

![Bar chart showing the percentage of patients who understood treatment recommendations in India and globally.](chart2)

India (n=106) | Global (n=1969)  
--- | ---  
Yes, completely | 44% | 55%  
Yes, to some extent | 51% | 36%  
No, this was not explained | 5% | 9%  

IKCC Global Patient Survey 2022 | India
Results: Diagnosis

Figure 11. Q11_5+ – When planning your treatments, were the following explained in a way you could understand? – Risk of recurrence

Figure 12. Q11_6+ – When planning your treatments, were the following explained in a way you could understand? – Likelihood of surviving your cancer beyond five years
Results: Developing a treatment plan/ shared decision making

The data presented in this section are from questions that asked about developing a treatment plan and shared decision making.

46% of respondents (n=49) reported that they were definitely involved as much as they wanted to be in developing their treatment plan, compared to 48% globally (n=992) (Figure 13; Q13+).

Figure 13. Q13+ - Were you involved as much as you wanted to be in decisions about your treatment plan?

Figure 14. Q14 - Who or what else helped you make decisions about your treatment plan? [multiple choice]
Results: Kidney Cancer care and treatment

Barriers to treatment

The data presented in this section are from questions that asked about care and treatment.

0% of respondents (n=0) reported experiencing no barriers to treatment, relative to 46% globally (n=953) (Figure 15; Q15).

The most commonly experienced barrier to treatment reported in India was Cost of treatment (82%, n=88).

Figure 15. Q15 - Which barriers (if any) have you experienced that affected your treatment choices for your kidney cancer or kidney growth? [multiple choice]

<table>
<thead>
<tr>
<th>Barrier</th>
<th>India (n=107)</th>
<th>Global (n=2085)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost of treatment</td>
<td></td>
<td>82%</td>
</tr>
<tr>
<td>Lack of access to treatment centre/prohibitive travel</td>
<td></td>
<td>35%</td>
</tr>
<tr>
<td>Language/inability to understand the treatment</td>
<td></td>
<td>20%</td>
</tr>
<tr>
<td>Lack of access to the most up-to-date treatment or equipment</td>
<td></td>
<td>19%</td>
</tr>
<tr>
<td>Wait time to treatment was an issue for me</td>
<td></td>
<td>50%</td>
</tr>
<tr>
<td>Lack of personal support</td>
<td></td>
<td>19%</td>
</tr>
<tr>
<td>No speciality doctor locally</td>
<td></td>
<td>15%</td>
</tr>
<tr>
<td>Difficulty managing my carer/caregiver role (child, parent, disabled person) while in treatment</td>
<td></td>
<td>20%</td>
</tr>
<tr>
<td>Fear of discrimination if my employer/friends/family knew about my disease</td>
<td></td>
<td>18%</td>
</tr>
<tr>
<td>No available treatments</td>
<td></td>
<td>15%</td>
</tr>
<tr>
<td>I experienced no barriers</td>
<td></td>
<td>0%</td>
</tr>
<tr>
<td>Other barrier not mentioned above</td>
<td></td>
<td>7%</td>
</tr>
</tbody>
</table>
Getting a second opinion

Respondents were asked whether they ever sought a second opinion about their kidney cancer (Figure 16: Q12). In India:

46% (n=49) did seek a second opinion
42% (n=45) reported this was not available to them
12% (n=13) stated they had never considered seeking a second opinion
0% (n=0) said seeking a second opinion was not necessary

Figure 16. Q12 - Did you ever seek a second opinion about your kidney cancer?
Results: Care and treatment today

The data presented in this section are from questions that asked about care today (at time of survey completion).

At the time of completing the survey (Figure 17; Q16):

- **49%** (n=52) had no evidence of disease / were cured
- **42%** (n=44) reported their kidney cancer / tumour remained localised (Stage 1 or 2)
- **8%** (n=8) reported their kidney cancer / tumour was advanced / metastasised (Stage 3 or 4)

**Figure 17. Q16 - Which of the following best describes your stage of kidney cancer or kidney growth TODAY?**

- **I currently have no evidence of disease**
  - India (n=106): 34%
  - Global (n=1993): 31%
- **I was told that I am cured**
  - India (n=106): 15%
  - Global (n=1993): 7%
- **Kidney cancer / growth is still only within the kidney (Stage 1 or Stage 2)**
  - India (n=106): 42%
  - Global (n=1993): 10%
- **Kidney cancer / growth is still locally advanced (Stage 3)**
  - India (n=106): 7%
  - Global (n=1993): 6%
- **Kidney cancer / growth has spread to other organs or distant sites (Stage 4)**
  - India (n=106): 1%
  - Global (n=1993): 36%
- **Don’t know / Can’t remember**
  - India (n=106): 2%
  - Global (n=1993): 3%
- **Other**
  - India (n=106): 0%
  - Global (n=1993): 8%

**Figure 18. Q17 - Where are you CURRENTLY being treated or followed?**

- **At a community, local or general hospital**
  - India (n=97): 14%
  - Global (n=1983): 38%
- **At a major cancer centre**
  - India (n=97): 74%
  - Global (n=1983): 43%
- **At a private clinic**
  - India (n=97): 10%
  - Global (n=1983): 8%
- **I am not currently being treated or followed anywhere**
  - India (n=97): 1%
  - Global (n=1983): 4%
- **Other**
  - India (n=97): 0%
  - Global (n=1983): 7%
Results: Care and treatment today

Understanding of medical care and treatment

The survey asked respondents to consider their level of understanding of their care and treatment at the time of completing the survey (Q18+, Q19+):

In India, respondents were most likely to completely understand:
- The importance of good nutrition for my well-being (51%, n=54) (Figure 27; Q19_2+)
- Complementary therapies (e.g. meditation, etc.) (51%, n=54) (Figure 29; Q19_4+)
- Targeted therapy options (pills or tablets) (50%, n=53) (Figure 21; Q18_3+)

In contrast, India respondents were least likely to completely understand:
- Adjuvant therapy (treatment aimed at reducing the chance of recurrence after surgery) (24%, n=25) (Figure 25; Q18_7+)
- Ablative therapy options (cryoablation or radiofrequency ablation) (24%, n=25) (Figure 23; Q18_5+)
- Active surveillance (27%, n=28) (Figure 24; Q18_6+)

Figure 19. Q18_1+ - Do you understand the following? – Surgical options
Results: Care and treatment today

**Figure 20. Q18_2+ – Do you understand the following? – Immunotherapy options**

<table>
<thead>
<tr>
<th></th>
<th>India (n=106)</th>
<th>Global (n=1723)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>40%</td>
<td>53%</td>
</tr>
<tr>
<td>Yes, to some extent</td>
<td>42%</td>
<td>30%</td>
</tr>
<tr>
<td>No</td>
<td>19%</td>
<td>18%</td>
</tr>
</tbody>
</table>

**Figure 21. Q18_3+ - Do you understand the following? - Targeted therapy options (pills or tablets)**

<table>
<thead>
<tr>
<th></th>
<th>India (n=106)</th>
<th>Global (n=1707)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>50%</td>
<td>52%</td>
</tr>
<tr>
<td>Yes, to some extent</td>
<td>42%</td>
<td>29%</td>
</tr>
<tr>
<td>No</td>
<td>8%</td>
<td>19%</td>
</tr>
</tbody>
</table>
Results: Care and treatment today

Figure 22. Q18_4+ – Do you understand the following? – Radiation therapy options

- India (n=106)
- Global (n=1639)

![Bar chart showing understanding levels for radiation therapy options in India and globally.](chart)

Figure 23. Q18_5+ - Do you understand the following? - Ablative therapy options (cryoablation or radiofrequency ablation)

- India (n=104)
- Global (n=1639)

![Bar chart showing understanding levels for ablative therapy options in India and globally.](chart)
Figure 24. Q18_6+ – Do you understand the following? – Active surveillance

<table>
<thead>
<tr>
<th></th>
<th>India (n=104)</th>
<th>Global (n=1747)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>27%</td>
<td>52%</td>
</tr>
<tr>
<td>Yes, to some extent</td>
<td>27%</td>
<td>53%</td>
</tr>
<tr>
<td>No</td>
<td>20%</td>
<td>22%</td>
</tr>
</tbody>
</table>

Figure 25. Q18_7+ - Do you understand the following? - Adjuvant therapy (treatment aimed at reducing the chance of recurrence after surgery)

<table>
<thead>
<tr>
<th></th>
<th>India (n=105)</th>
<th>Global (n=1608)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>24%</td>
<td>29%</td>
</tr>
<tr>
<td>Yes, to some extent</td>
<td>27%</td>
<td>54%</td>
</tr>
<tr>
<td>No</td>
<td>22%</td>
<td>44%</td>
</tr>
</tbody>
</table>
Results: Care and treatment today

Understanding of supportive care

Figure 26. Q19_1+ – Do you understand the following? – Palliative/ supportive care

![Bar chart showing understanding of supportive care](chart1)

- Yes: India (33%) vs Global (51%)
- Yes, to some extent: India (37%) vs Global (30%)
- No: India (30%) vs Global (19%)

Figure 27. Q19_2+ - Do you understand the following? - The importance of good nutrition for my well-being

![Bar chart showing understanding of nutrition](chart2)

- Yes: India (51%) vs Global (58%)
- Yes, to some extent: India (41%) vs Global (34%)
- No: India (8%) vs Global (8%)
Results: Care and treatment today

Figure 28. Q19_3+ – Do you understand the following? – The importance of lifestyle choices for my wellbeing (e.g. avoiding smoking, being active)

- Yes: 50% (India) vs. 71% (Global)
- Yes, to some extent: 43% (India) vs. 25% (Global)
- No: 7% (India) vs. 4% (Global)

Figure 29. Q19_4+ - Do you understand the following? - Complementary therapies (e.g. meditation, etc.)

- Yes: 51% (India) vs. 38% (Global)
- Yes, to some extent: 42% (India) vs. 32% (Global)
- No: 7% (India) vs. 31% (Global)
Figure 30. Q19 5+ – Do you understand the following? – My local guidelines for kidney cancer care and follow up

- Yes: 49% (India), 43% (Global)
- Yes, to some extent: 45% (India), 35% (Global)
- No: 6% (India), 22% (Global)
Results: Biopsy and active surveillance for small renal mass

Management of small renal masses

Respondents were asked about their willingness to participate in biopsy and active surveillance. Of India respondents:

50% (n=53) reported that they would be willing to participate in active surveillance with regular imaging such as ultrasound and CT if their doctor recommended this (Figure 31; Q20).

52% (n=55) would be willing to have a biopsy of the small renal growth if it might change the treatment decision (Figure 32; Q21).

Respondents were then asked how long they would prefer to have regular imaging scans (ultrasound or CT) for surveillance following surgery for their kidney cancer or kidney growth (Figure 33; Q22). In India, respondents were most likely to prefer this form of surveillance for Less than 2 years (58%, n=61). Globally, respondents preferred length of surveillance was less than 2 years (32%, n=638).

Figure 31. Q20 - When a small renal growth (less than 4 cm) is detected on a scan, it can often be managed without invasive treatment such as surgery. If your doctor recommended Active Surveillance with regular imaging such as ultrasound and CT, would you be willing to participate?

![Bar chart showing responses to Q20 for India and Global.]

- Yes: India (50%) vs Global (62%)
- No: India (42%) vs Global (20%)
- Don’t know: India (8%) vs Global (18%)
Figure 32. Q21 – A biopsy of a small renal growth (less than 4 cm) might provide doctors with more information to help them form a more precise diagnosis and treatment plan for your individual case. Would you be willing to have a biopsy of the small renal growth if it might change the treatment decision?

<table>
<thead>
<tr>
<th></th>
<th>India (n=105)</th>
<th>Global (n=1949)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>52%</td>
<td>68%</td>
</tr>
<tr>
<td>No</td>
<td>46%</td>
<td>17%</td>
</tr>
<tr>
<td>Don't know</td>
<td>2%</td>
<td>15%</td>
</tr>
</tbody>
</table>

Results: Biopsy and active surveillance for small renal mass

Figure 33. Q22 - Following surgery for your kidney cancer or kidney growth, how long would you PREFER to have regular imaging scans (ultrasound or CT) for surveillance?

<table>
<thead>
<tr>
<th></th>
<th>India (n=106)</th>
<th>Global (n=1965)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 2 years</td>
<td>32%</td>
<td>58%</td>
</tr>
<tr>
<td>2 to 4 years</td>
<td>6%</td>
<td>32%</td>
</tr>
<tr>
<td>4 to 6 years</td>
<td>1%</td>
<td>7%</td>
</tr>
<tr>
<td>More than 6 years</td>
<td>0%</td>
<td>23%</td>
</tr>
<tr>
<td>Don’t know</td>
<td>8%</td>
<td>4%</td>
</tr>
</tbody>
</table>

I would decide based on my healthcare team’s opinion

<table>
<thead>
<tr>
<th></th>
<th>India (n=105)</th>
<th>Global (n=1949)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>2%</td>
<td>28%</td>
</tr>
</tbody>
</table>
Results: Quality of life

Current level of physical activity

The data presented in this section are from questions that asked about quality of life.

In India, 49% (n=52) of respondents reported their current level of physical activity to be within (151-300 minutes per week) or above (≥300 minutes per week) physical activity guidelines (Figure 34; Q23+).

This is compared to 31% (n=33) who reported they were not at all active (less than 100 minutes of physical activity per week) and 20% (n=21) who stated they were not very active (between 101-150 minutes of physical activity per week).

Figure 34. Q23+ - I would describe my current level of physical activity (defined as physical activity that lasts at least 10 minutes) as:

- Not at all active (Less than 100 minutes physical activity per week) - 31% (India) vs 19% (Global)
- Not very active (101-150 minutes of physical activity per week) - 20% (India) vs 27% (Global)
- Within physical activity guidelines (151-300 minutes of physical activity per week) - 19% (India) vs 36% (Global)
- Above physical activity guidelines (≥300 minutes of physical activity per week) - 30% (India) vs 19% (Global)
Results: Quality of life

The survey asked respondents how often various symptoms, feelings and concerns had an impact on their sense of emotional well-being since their diagnosis (Figures 35 to 47; Q24, Q25).

In India, respondents were most likely to report they always, very often or sometimes experienced:

- General anxiety (100%, n=106) (Figure 35; Q24_1)
- Disease-related anxiety (100%, n=106) (Figure 36; Q24_2)
- Stress related to financial issues (99%, n=105) (Figure 43; Q25_3)
- Loss/reduction in employment (99%, n=105) (Figure 44; Q25_4)
- Problems getting health or life insurance coverage (99%, n=105) (Figure 46; Q25_6)

General anxiety

Figure 35. Q24_1 - How often have the following impacted your sense of emotional well-being since your diagnosis? – General anxiety

<table>
<thead>
<tr>
<th></th>
<th>India (n=106)</th>
<th>Global (n=2068)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>55%</td>
<td></td>
</tr>
<tr>
<td>Very often</td>
<td>40%</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td>reat is not available</td>
<td>34%</td>
</tr>
<tr>
<td>Rarely</td>
<td>6%</td>
<td>16%</td>
</tr>
<tr>
<td>Never</td>
<td>6%</td>
<td>0%</td>
</tr>
</tbody>
</table>
Results: Quality of life

Disease-related anxiety

Figure 36. Q24.2 – How often have the following impacted your sense of emotional well-being since your diagnosis? – Disease-related anxiety

<table>
<thead>
<tr>
<th></th>
<th>India (n=106)</th>
<th>Global (n=2049)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>34%</td>
<td>20%</td>
</tr>
<tr>
<td>Very often</td>
<td>52%</td>
<td>31%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>34%</td>
<td>14%</td>
</tr>
<tr>
<td>Rarely</td>
<td>0%</td>
<td>11%</td>
</tr>
<tr>
<td>Never</td>
<td>0%</td>
<td>4%</td>
</tr>
</tbody>
</table>

Fear of dying

Figure 37. Q24.3 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Fear of dying

<table>
<thead>
<tr>
<th></th>
<th>India (n=106)</th>
<th>Global (n=2049)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>35%</td>
<td>15%</td>
</tr>
<tr>
<td>Very often</td>
<td>54%</td>
<td>21%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>34%</td>
<td>9%</td>
</tr>
<tr>
<td>Rarely</td>
<td>0%</td>
<td>20%</td>
</tr>
<tr>
<td>Never</td>
<td>0%</td>
<td>9%</td>
</tr>
</tbody>
</table>
Results: Quality of life

Fear of the cancer/growth coming back (recurrence)

Figure 38. Q24_4 – How often have the following impacted your sense of emotional well-being since your diagnosis? – Fear of the cancer/growth coming back (recurrence)

Sadness or depression

Figure 39. Q24_5 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Sadness or depression
Results: Quality of life

Isolation

Figure 40. Q24_6 – How often have the following impacted your sense of emotional well-being since your diagnosis? – Isolation

<table>
<thead>
<tr>
<th></th>
<th>India (n=105)</th>
<th>Global (n=2049)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>32%</td>
<td>9%</td>
</tr>
<tr>
<td>Very often</td>
<td>50%</td>
<td>17%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>27%</td>
<td>15%</td>
</tr>
<tr>
<td>Rarely</td>
<td>23%</td>
<td>2%</td>
</tr>
<tr>
<td>Never</td>
<td>24%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Changes in relationships with loved ones, friends or co-workers

Figure 41. Q25_1 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Changes in relationships with loved ones, friends or co-workers

<table>
<thead>
<tr>
<th></th>
<th>India (n=106)</th>
<th>Global (n=2061)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>36%</td>
<td>11%</td>
</tr>
<tr>
<td>Very often</td>
<td>48%</td>
<td>21%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>30%</td>
<td>14%</td>
</tr>
<tr>
<td>Rarely</td>
<td>18%</td>
<td>2%</td>
</tr>
<tr>
<td>Never</td>
<td>20%</td>
<td>0%</td>
</tr>
</tbody>
</table>
Results: Quality of life

Difficulty in daily living, on the job or in school

Figure 42. Q25.2 – How often have the following impacted your sense of emotional well-being since your diagnosis? – Difficulty in daily living, on the job or in school

- Always
  - India (n=106): 25%
  - Global (n=2046): 11%
- Very often
  - India (n=106): 55%
  - Global (n=2046): 23%
- Sometimes
  - India (n=106): 17%
  - Global (n=2046): 28%
- Rarely
  - India (n=106): 20%
  - Global (n=2046): 2%
- Never
  - India (n=106): 17%
  - Global (n=2046): 2%

Stress related to financial issues

Figure 43. Q25.3 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Stress related to financial issues

- Always
  - India (n=106): 42%
  - Global (n=2048): 38%
- Very often
  - India (n=106): 12%
  - Global (n=2048): 17%
- Sometimes
  - India (n=106): 20%
  - Global (n=2048): 26%
- Rarely
  - India (n=106): 1%
  - Global (n=2048): 21%
- Never
  - India (n=106): 0%
  - Global (n=2048): 24%
Results: Quality of life

Loss/reduction in employment

Figure 44. Q25.4 – How often have the following impacted your sense of emotional well-being since your diagnosis? – Loss/reduction in employment

- India (n=106)  - Global (n=2029)

<table>
<thead>
<tr>
<th>Always</th>
<th>Very often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>33%</td>
<td>48%</td>
<td>15%</td>
<td>14%</td>
<td>1%</td>
</tr>
</tbody>
</table>

Difficulty navigating the healthcare system

Figure 45. Q25.5 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Difficulty navigating the healthcare system

- India (n=106)  - Global (n=2023)

<table>
<thead>
<tr>
<th>Always</th>
<th>Very often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>35%</td>
<td>46%</td>
<td>15%</td>
<td>4%</td>
<td>0%</td>
</tr>
</tbody>
</table>
Results: Quality of life

Problems getting health or life insurance coverage

Figure 46. Q25_6 – How often have the following impacted your sense of emotional well-being since your diagnosis? – Problems getting health or life insurance coverage

<table>
<thead>
<tr>
<th></th>
<th>India (n=106)</th>
<th>Global (n=2020)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>31%</td>
<td>47%</td>
</tr>
<tr>
<td>Very often</td>
<td>13%</td>
<td>14%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>21%</td>
<td>19%</td>
</tr>
<tr>
<td>Rarely</td>
<td>0%</td>
<td>14%</td>
</tr>
<tr>
<td>Never</td>
<td>1%</td>
<td>40%</td>
</tr>
</tbody>
</table>

Concerns about body image/changes in physical appearance

Figure 47. Q25_7 – How often have the following impacted your sense of emotional well-being since your diagnosis? – Concerns about body image/changes in physical appearance

<table>
<thead>
<tr>
<th></th>
<th>India (n=106)</th>
<th>Global (n=2025)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>28%</td>
<td>55%</td>
</tr>
<tr>
<td>Very often</td>
<td>11%</td>
<td>17%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>13%</td>
<td>26%</td>
</tr>
<tr>
<td>Rarely</td>
<td>4%</td>
<td>20%</td>
</tr>
<tr>
<td>Never</td>
<td>0%</td>
<td>25%</td>
</tr>
</tbody>
</table>
Results: Quality of life

Respondents who reported they always, very often, or sometimes experienced a symptom, feeling or concern that impacted their sense of emotional well-being since their diagnosis (Q24; Q25) were then asked if they had ever talked to their doctor or any other healthcare professional about any of their concerns. 57% (n=55) stated they had discussed their concerns and the doctor or healthcare professional were very helpful (Figure 48; Q27+). This is compared to 36% (n=547) globally.

Figure 48. Q27+ – Have you ever talked to your doctor or to any other healthcare professional about any of your concerns?

Figure 49. Q28 – Have you ever used a patient support group (either in person or online) to help you with your kidney cancer / growth?
Results: Perspectives on Kidney Cancer clinical trials

The data presented in this section are from questions that asked about Kidney Cancer clinical trials.

Awareness of clinical trials

In India, 39% of respondents (n=41) reported they had been asked by a health professional to consider participating in a cancer clinical trial when they were first diagnosed, while 22% (n=23) were asked when their cancer recurred (Figure 51; Q30).

**Figure 50. Q29 - Who, if anyone, has discussed cancer clinical trials with you? [multiple choice]**

<table>
<thead>
<tr>
<th>Choice</th>
<th>India (n=106)</th>
<th>Global (n=2031)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No one</td>
<td>3%</td>
<td>39%</td>
</tr>
<tr>
<td>Doctor / Nurse</td>
<td>14%</td>
<td>26%</td>
</tr>
<tr>
<td>Spouse, friend or family</td>
<td>18%</td>
<td>37%</td>
</tr>
<tr>
<td>Patient organisation or support group</td>
<td>0%</td>
<td>3%</td>
</tr>
<tr>
<td>Other</td>
<td>6%</td>
<td>30%</td>
</tr>
<tr>
<td>Don’t know / Can’t remember</td>
<td>6%</td>
<td>30%</td>
</tr>
</tbody>
</table>

**Figure 51. Q30 - Have you ever been asked by a health professional to consider participating in a cancer clinical trial?**

<table>
<thead>
<tr>
<th>Response</th>
<th>India (n=106)</th>
<th>Global (n=2031)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, when I was first diagnosed</td>
<td>39%</td>
<td>56%</td>
</tr>
<tr>
<td>Yes, when my cancer recurred</td>
<td>22%</td>
<td>29%</td>
</tr>
<tr>
<td>No</td>
<td>10%</td>
<td>6%</td>
</tr>
<tr>
<td>Don’t know / can’t remember</td>
<td>26%</td>
<td>37%</td>
</tr>
<tr>
<td>I do not know of any clinical trials in my country</td>
<td>0%</td>
<td>3%</td>
</tr>
</tbody>
</table>
Results: Perspectives on Kidney Cancer clinical trials

Taking part in clinical trials

Of those who were asked to participate in a cancer clinical trial, 19% of respondents (n=12) in India agreed to participate, relative to 70% (n=498) globally (Figure 52; Q31).

Figure 52. Q31 – Did you agree to participate in the cancer clinical trial?

<table>
<thead>
<tr>
<th></th>
<th>India (n=63)</th>
<th>Global (n=715)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>19%</td>
<td>70%</td>
</tr>
<tr>
<td>No</td>
<td>81%</td>
<td>26%</td>
</tr>
<tr>
<td>Don't know / Can't remember</td>
<td>0%</td>
<td>4%</td>
</tr>
</tbody>
</table>

Figure 53. Q32 – Why did you agree to participate? [multiple choice]

- My doctor recommended it
  - India (n=12): 92%
  - Global (n=496): 60%
- I thought it might offer better care
  - India (n=12): 8%
  - Global (n=496): 50%
- I wanted a specific type of treatment
  - India (n=12): 8%
  - Global (n=496): 16%
- It was my only option for treatment
  - India (n=12): 0%
  - Global (n=496): 17%
- I wanted to help kidney cancer research
  - India (n=12): 0%
  - Global (n=496): 43%
- Financial reasons
  - India (n=12): 0%
  - Global (n=496): 67%
- Don't know / Can't remember
  - India (n=12): 0%
  - Global (n=496): 0%
- Other
  - India (n=12): 5%
Results: Perspectives on Kidney Cancer clinical trials

Of those who participated in a cancer clinical trial, **100%** (n=12) were very satisfied or satisfied with their overall experience. This is in comparison to **65%** (n=313) globally (Figure 54; Q33).

All respondents were asked how likely is it that they would participate in a cancer clinical trial if they were invited in future. In India, **60%** (n=64) reported they were very likely or likely to participate, compared to **71%** (n=1445) globally (Figure 55; Q35).

**Figure 54. Q33 – How satisfied were you overall with your cancer clinical trial experience?**

<table>
<thead>
<tr>
<th>Satisfied Levels</th>
<th>India (n=12)</th>
<th>Global (n=485)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very satisfied</td>
<td>25%</td>
<td>33%</td>
</tr>
<tr>
<td>Satisfied</td>
<td>75%</td>
<td>65%</td>
</tr>
<tr>
<td>Neither satisfied nor dissatisfied</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>0%</td>
<td>4%</td>
</tr>
<tr>
<td>Very dissatisfied</td>
<td>0%</td>
<td>4%</td>
</tr>
</tbody>
</table>

**Figure 55. Q35 - In the future if you were invited, how likely is it that you would participate in a cancer clinical trial?**

<table>
<thead>
<tr>
<th>Likely Levels</th>
<th>India (n=106)</th>
<th>Global (n=2032)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very likely</td>
<td>6%</td>
<td>39%</td>
</tr>
<tr>
<td>Likely</td>
<td>32%</td>
<td>55%</td>
</tr>
<tr>
<td>Neither likely nor unlikely</td>
<td>9%</td>
<td>19%</td>
</tr>
<tr>
<td>Unlikely</td>
<td>25%</td>
<td>6%</td>
</tr>
<tr>
<td>Very unlikely</td>
<td>5%</td>
<td>4%</td>
</tr>
</tbody>
</table>
A new question introduced into the 2022 survey asked respondents about genetic testing (Figure 56; Q36). Of respondents in India:

- **33%** (n=35) had none of the risk factors
- **38%** (n=40) had some of the risk factors but were not offered genetic testing
- **2%** (n=2) had some of the risk factors and genetic testing was offered / had been completed

**Figure 56. Q36 - Being diagnosed when you are under 46 years old, having a family history of kidney cancer or having bilateral disease may increase the chance of your kidney cancer being hereditary (caused by genetic changes passed down from parent to child). Currently less than 20% of all kidney cancers are thought to be hereditary.**

**Has anyone on your healthcare team discussed genetic testing with you?**

<table>
<thead>
<tr>
<th>Response</th>
<th>India (n=106)</th>
<th>Global (n=2006)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No, I have none of the above risk factors</td>
<td>33%</td>
<td>53%</td>
</tr>
<tr>
<td>Yes, I have some of the above risk factors but I was not offered genetic testing</td>
<td>38%</td>
<td>19%</td>
</tr>
<tr>
<td>Yes, I have some of the above risk factors and genetic testing was offered to me / has been completed</td>
<td>2%</td>
<td>17%</td>
</tr>
<tr>
<td>Unsure/ can't remember</td>
<td>27%</td>
<td>11%</td>
</tr>
</tbody>
</table>
Positive scores

The following tables contain ‘positive scores’. Positive scores are a summary measure used to compare country data against global data.

The positive score shows the percentage of respondents who gave a favourable response to applicable questions. Not all questions will have a positive score; exceptions include demographic details such as gender, ethnic group, or age. Higher scores indicate more positive results.

Example score table:

<table>
<thead>
<tr>
<th>Would you be willing to have a biopsy?</th>
<th>Your country</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base (all respondents)</td>
<td>200</td>
</tr>
<tr>
<td>Strongly disagree</td>
<td>20</td>
</tr>
<tr>
<td>Disagree</td>
<td>35</td>
</tr>
<tr>
<td>Neither agree nor disagree</td>
<td>45</td>
</tr>
<tr>
<td>Agree</td>
<td>35</td>
</tr>
<tr>
<td>Strongly agree</td>
<td>65</td>
</tr>
</tbody>
</table>

Positive responses are combined resulting in 50% of respondents (n=100) agreed to have a biopsy.

Significance testing

We identify questions where there are significant differences between your country and global average. By 'significant' difference, we mean the scores between your country and the global results are statistically significant with a confidence level of 95%. We are therefore reasonably confident that the result reflects a real difference.

The calculation used to test the statistical significance of scores is the Agresti-Coull modification of the “z-test”. The Z-test calculates the differences between two proportions. Any result where the value of Z is greater than 1.96 is marked as “statistically significant”.

In the following tables, coloured cells show where your positive score is significantly different to the global average. Green cells indicate a significantly higher score than the global average, and red cells show a significantly lower score than the global average.

Please note that there are differences in kidney cancer care provision between countries, as well as differences in the profile of respondents globally. For this reason, caution should be taken when comparing country results to global data.
## Comparisons to global findings

<table>
<thead>
<tr>
<th>Section</th>
<th>Question</th>
<th>India</th>
<th>Global</th>
<th>n</th>
<th>score</th>
<th>n</th>
<th>score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>Informed of sub-type of kidney cancer or growth when first diagnosed (Q8)</td>
<td>95</td>
<td>58%</td>
<td>1979</td>
<td>36%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Diagnosed within 3 months or less from time patient first thought something might be wrong (Q10)</td>
<td>106</td>
<td>90%</td>
<td>1968</td>
<td>71%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Stage of cancer completely explained when planning treatments (Q11_1)</td>
<td>106</td>
<td>46%</td>
<td>2074</td>
<td>48%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sub-type of cancer completely explained when planning treatments (Q11_2)</td>
<td>105</td>
<td>30%</td>
<td>1853</td>
<td>33%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Treatment options completely explained when planning treatments (Q11_3)</td>
<td>106</td>
<td>50%</td>
<td>2001</td>
<td>54%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Treatment recommendations completely explained when planning treatments (Q11_4)</td>
<td>106</td>
<td>44%</td>
<td>1969</td>
<td>55%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Risk of recurrence completely explained when planning treatments (Q11_5)</td>
<td>106</td>
<td>37%</td>
<td>1923</td>
<td>34%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Likelihood of surviving cancer beyond five years completely explained when planning treatments (Q11_6)</td>
<td>105</td>
<td>25%</td>
<td>1925</td>
<td>28%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developing a treatment plan</td>
<td>Definitely involved in decisions about treatment plan as much as wanted to be (Q13)</td>
<td>107</td>
<td>46%</td>
<td>2051</td>
<td>48%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Key:**  
- Green: significantly higher than global  
- Red: significantly lower than global, *"* = suppressed
## Comparisons to global findings

<table>
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<tr>
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<th>score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your care and treatment</td>
<td>Experienced no barriers that affected treatment choices (Q15)</td>
<td>107</td>
<td>2085</td>
<td>0%</td>
<td>46%</td>
</tr>
<tr>
<td></td>
<td>Understands surgical options (Q18_1)</td>
<td>105</td>
<td>1887</td>
<td>41%</td>
<td>72%</td>
</tr>
<tr>
<td></td>
<td>Understands immunotherapy options (Q18_2)</td>
<td>106</td>
<td>1723</td>
<td>40%</td>
<td>53%</td>
</tr>
<tr>
<td></td>
<td>Understands targeted therapy options (pills or tablets) (Q18_3)</td>
<td>106</td>
<td>1707</td>
<td>50%</td>
<td>52%</td>
</tr>
<tr>
<td></td>
<td>Understands radiation therapy options (Q18_4)</td>
<td>106</td>
<td>1639</td>
<td>43%</td>
<td>46%</td>
</tr>
<tr>
<td></td>
<td>Understands ablative therapy options (cryoablation or radiofrequency ablation) (Q18_5)</td>
<td>104</td>
<td>1633</td>
<td>24%</td>
<td>32%</td>
</tr>
<tr>
<td></td>
<td>Understands active surveillance (Q18_6)</td>
<td>104</td>
<td>1747</td>
<td>27%</td>
<td>52%</td>
</tr>
<tr>
<td></td>
<td>Understands adjuvant therapy (treatment aimed at reducing the chance of recurrence after surgery) (Q18_7)</td>
<td>105</td>
<td>1608</td>
<td>24%</td>
<td>29%</td>
</tr>
<tr>
<td></td>
<td>Understands palliative/ supportive care (Q19_1)</td>
<td>106</td>
<td>1795</td>
<td>33%</td>
<td>51%</td>
</tr>
<tr>
<td></td>
<td>Understands the importance of good nutrition for my well-being (Q19_2)</td>
<td>106</td>
<td>1928</td>
<td>51%</td>
<td>58%</td>
</tr>
<tr>
<td></td>
<td>Understands the importance of lifestyle choices for my wellbeing (e.g. avoiding smoking, being active) (Q19_3)</td>
<td>106</td>
<td>1936</td>
<td>50%</td>
<td>71%</td>
</tr>
<tr>
<td></td>
<td>Understands complementary therapies (e.g. meditation, etc.) (Q19_4)</td>
<td>106</td>
<td>1828</td>
<td>51%</td>
<td>38%</td>
</tr>
<tr>
<td></td>
<td>Understands local guidelines for kidney cancer care and follow up (Q19_5)</td>
<td>106</td>
<td>1866</td>
<td>49%</td>
<td>43%</td>
</tr>
</tbody>
</table>

*Key:  green = significantly higher than global, red = significantly lower than global, ‘*’ = suppressed*
<table>
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<th>score</th>
<th>n</th>
<th>score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of life</td>
<td>Physical activity within or above physical activity guidelines (≥ 151 minutes per week) (Q23)</td>
<td>106</td>
<td>49%</td>
<td>2017</td>
<td>54%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never/ rarely experienced general anxiety since diagnosis (Q24_1)</td>
<td>106</td>
<td>0%</td>
<td>2068</td>
<td>21%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never/ rarely experienced disease-related anxiety since diagnosis (Q24_2)</td>
<td>106</td>
<td>0%</td>
<td>2049</td>
<td>15%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never/ rarely experienced fear of dying since diagnosis (Q24_3)</td>
<td>106</td>
<td>2%</td>
<td>2054</td>
<td>29%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never/ rarely experienced fear of the cancer/growth coming back (recurrence) since diagnosis (Q24_4)</td>
<td>105</td>
<td>1%</td>
<td>2034</td>
<td>13%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never/ rarely experienced sadness or depression since diagnosis (Q24_5)</td>
<td>105</td>
<td>3%</td>
<td>2056</td>
<td>32%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never/ rarely experienced isolation since diagnosis (Q24_6)</td>
<td>105</td>
<td>2%</td>
<td>2049</td>
<td>47%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never/ rarely experienced changes in relationships with loved ones, friends or co-workers since diagnosis (Q25_1)</td>
<td>106</td>
<td>2%</td>
<td>2061</td>
<td>37%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never/ rarely experienced difficulty in daily living, on the job or in school since diagnosis (Q25_2)</td>
<td>106</td>
<td>4%</td>
<td>2046</td>
<td>38%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never/ rarely experienced stress related to financial issues since diagnosis (Q25_3)</td>
<td>106</td>
<td>1%</td>
<td>2048</td>
<td>45%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never/ rarely experienced loss/reduction in employment since diagnosis (Q25_4)</td>
<td>106</td>
<td>1%</td>
<td>2029</td>
<td>54%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never/ rarely experienced difficulty navigating the healthcare system since diagnosis (Q25_5)</td>
<td>106</td>
<td>4%</td>
<td>2043</td>
<td>44%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never/ rarely experienced problems getting health or life insurance coverage since diagnosis (Q25_6)</td>
<td>106</td>
<td>1%</td>
<td>2020</td>
<td>54%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never/ rarely experienced concerns about body image/changes in physical appearance since diagnosis (Q25_7)</td>
<td>106</td>
<td>4%</td>
<td>2035</td>
<td>45%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Doctor or healthcare professional very helpful when talking about concerns (Q27)</td>
<td>97</td>
<td>57%</td>
<td>1502</td>
<td>36%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Comparisons to global findings

*Key:  ![Green] significantly higher than global  ![Red] significantly lower than global, "*" = suppressed*

<table>
<thead>
<tr>
<th>Section</th>
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<th>Global</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer clinical trials</td>
<td>Very satisfied or satisfied with overall experience of cancer clinical trial (Q33)</td>
<td>12</td>
<td>485</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>n</th>
<th>score</th>
<th>n</th>
<th>score</th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td>100%</td>
<td>485</td>
<td>65%</td>
</tr>
</tbody>
</table>
Benchmarking charts

Benchmarking charts display how the positive score for your country compares to the range of scores across other countries. These can be useful for highlighting where there is room for improvement.

Please note that there are differences in kidney cancer care provision between countries, as well as differences in the profile of respondents globally. For this reason, caution should be taken when comparing country results to global data.

How to interpret the charts

Diagnosis (example data) 1

1. Informed of sub-type of kidney cancer or growth when first diagnosed (Q8)
2. Diagnosed within 3 months or less from time patient first thought something might be wrong (Q10)

KEY
1. Section of the questionnaire
2. Question number and positive score text (derived from survey question)
3. Green bar: range of positive scores for all countries
4. Red line: global average score
5. Yellow diamond: the score for your country
Benchmarking charts

**Diagnosis**

- Informed of sub-type of kidney cancer or growth when first diagnosed (Q8)
- Diagnosed within 3 months or less from time patient first thought something might be wrong (Q10)
- Stage of cancer completely explained when planning treatments (Q11_1)
- Sub-type of cancer completely explained when planning treatments (Q11_2)
- Treatment options completely explained when planning treatments (Q11_3)
- Treatment recommendations completely explained when planning treatments (Q11_4)
- Risk of recurrence completely explained when planning treatments (Q11_5)
- Likelihood of surviving cancer beyond five years completely explained when planning treatments (Q11_6)

**Developing a treatment plan**

- Definitely involved in decisions about treatment plan as much as wanted to be (Q13)
Benchmarking charts

Your care and treatment

Experienced no barriers that affected treatment choices (Q15)

Your care today

Understands surgical options (Q18_1)

Understands immunotherapy options (Q18_2)

Understands targeted therapy options (pills or tablets) (Q18_3)

Understands radiation therapy options (Q18_4)

Understands Ablative therapy options (cryoablation or radiofrequency ablation) (Q18_5)

Understands Active Surveillance (Q18_6)

Understands Adjuvant therapy (Q18_7)

Understands palliative/ supportive care (Q19_1)

Understands the importance of good nutrition for my well-being (Q19_2)

Understands the importance of lifestyle choices for my wellbeing (Q19_3)

Understands complementary therapies (e.g. meditation, etc.) (Q19_4)

Understands local guidelines for kidney cancer care and follow up (Q19_5)
Quality of life

Physical activity within or above physical activity guidelines (= 151 minutes per week) (Q23)

Never/rarely experienced general anxiety since diagnosis (Q24_1)

Never/rarely experienced disease-related anxiety since diagnosis (Q24_2)

Never/rarely experienced fear of dying since diagnosis (Q24_3)

Never/rarely experienced fear of the cancer/growth coming back (recurrence) since diagnosis (Q24_4)

Never/rarely experienced sadness or depression since diagnosis (Q24_5)

Never/rarely experienced isolation since diagnosis (Q24_6)

Never/rarely experienced changes in relationships with loved ones, friends or co-workers since diagnosis

Never/rarely experienced difficulty in daily living, on the job or in school since diagnosis (Q25_2)

Never/rarely experienced stress related to financial issues since diagnosis (Q25_3)

Never/rarely experienced loss/reduction in employment since diagnosis (Q25_4)

Never/rarely experienced difficulty navigating the healthcare system since diagnosis (Q25_5)

Never/rarely experienced problems getting health or life insurance coverage since diagnosis (Q25_6)

Never/rarely experienced concerns about body image/changes in physical appearance since diagnosis

Doctor or healthcare professional very helpful when talking about concerns (Q27)

N.B. Full reporting text: Q25_1 Never/rarely experienced changes in relationships with loved ones, friends or co-workers since diagnosis; Q25_7 Never/rarely experienced concerns about body image/changes in physical appearance since diagnosis
Very satisfied or satisfied with overall experience of cancer clinical trial (Q33)
Conclusions

This report presents data from residents of India from the International Kidney Cancer Coalition (IKCC) biennial Global Survey 2022, where patients and carers were invited to respond to enhance understanding of patient experiences of kidney cancer care. The survey data provides a wealth of valuable knowledge relating to patient experiences. These results need to be interpreted at the local level by the Affiliate Organisations to determine the actionable findings that they wish to address locally.

The IKCC and its global affiliates will be using the results to ensure that patient and caregiver voices are heard and acted upon. This information will furthermore help patient organisations and medical professionals better understand the patients’ state of mind, need for psychological supports to be able to attain the optimal state of mind, regardless of stage of disease.

Results will be broadly shared with the global kidney cancer medical communities for planning and sharing of best practice. Furthermore, individual countries can use their reports to advance their understanding of patient experiences and to drive improvements in care provision locally.

Acknowledgements

We would like to thank all members of the Global Patient Survey Steering Committee and Affiliate Organisations for their support and collaboration on this project.

The project was funded by (alphabetical order) Bristol Myers Squibb, Eisai, Exelixis, Ipsen, and MSD* in accordance with the IKCC Code of Conduct Governing Funding. Sponsors have not been involved in the survey programme at any stage.

Most importantly, we would like to thank the patients and caregivers who took the time to complete the 2022 survey. This report, and the work of the IKCC and our global affiliate organisations in response to this feedback, is dedicated to you all with our sincere appreciation.

*Partial Funding
Appendices

1. Frequency Tables – India (Available as a separate document)
2. Methodology (Available as a separate document)
3. Questionnaire (Available as a separate document)

The following reports are also available in this series:

- International Kidney Cancer Coalition Survey 2022 – Global
- International Kidney Cancer Coalition Survey 2022 – Country

Country specific reports where respondent numbers are greater or equal to 90. These include:

- Canada
- England
- France
- Germany
- India
- Japan
- Mexico
- Republic of Korea
- South Africa
- USA
International Kidney Cancer Coalition (IKCC)

The International Kidney Cancer Coalition (IKCC) is an independent international network of patient organisations that focus exclusively, or include a specific focus, on kidney cancer. The organisation was born from a very strong desire among national kidney cancer patient groups to network, cooperate and share materials, knowledge, and experiences from around the world. Priority areas of focus include:

- Strengthening the capacity of current and emerging affiliates in their support for patients with kidney cancer
- Advocating for access to the best care
- Increasing awareness of kidney cancer globally
- Being a global authority in the provision of credible and up-to-date kidney cancer information
- Fostering projects promoting the voice of kidney cancer patients in research activities worldwide

Legally incorporated as a foundation registered in The Netherlands under: Stichting International Kidney Cancer Coalition | Registered No KvK 62070665 | Website: https://ikcc.org/

Picker

Picker is a leading international health and social care charity. We carry out research to understand individuals’ needs and their experiences of care. We are here to:

- Influence policy and practice so that health and social care systems are always centred around people’s needs and preferences.
- Inspire the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood.
- Empower those working in health and social care to improve experiences by effectively measuring, and acting upon, people’s feedback.

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