



International Kidney Cancer Coalition Global Survey 2022

Global Report

August 2023

Prepared by: Picker for the
International Kidney Cancer Coalition

picker.org

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

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- 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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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.

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 15 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 2,213 patient and carer/caregiver responses across 39 countries globally.

The results in this report present the global data from all worldwide respondents. It is supplemented with country-specific reports (where respondent numbers allow).

Executive summary

The 2022 Global Survey achieved 2,213 patient and carer/caregiver responses across 39 countries globally. The survey was published online in 15 languages and promoted through IKCC affiliates and partners, as well as via the IKCC social media and web pages, between September and November 2022. As in previous years, the survey captured respondents' understanding and experience of:

- Patient knowledge, expectations of treatment and shared decision making
- Quality of life and barriers to treatment
- Clinical trials and research awareness

Newly introduced questions in 2022 sought insight on the following:

- Small renal masses including biopsy and surveillance
- Surveillance preferences following surgery
- Genetic testing.

Understanding of diagnosis, treatment options, medical care and treatment

There are several areas where patients indicated a lack of understanding of their diagnosis, treatment options, medical care and treatment. Of particular concern, 42% of respondents reported that the likelihood of surviving their cancer beyond five years was not explained when planning their treatments. The repercussions of not having this information are hugely impactful to patients and can have a multitude of implications for their psychological wellbeing, treatment decisions and life planning.

Awareness of medical treatment was particularly low for adjuvant therapy (treatment aimed at reducing the chance of recurrence after surgery) with 44% of respondents reporting they did not understand this form of treatment. Medical professionals must ensure people using healthcare services receive reliable, high quality and accessible information at every stage of their journey. Information should be provided at appropriate times, in an understandable way, and should support people to make informed decisions and manage their own care.

Half of respondents (52%) indicated they were not involved as much as they wanted to be in developing their treatment plan. Empowering patients to make informed decisions about their treatment is central to providing patient centered care.

Emotional wellbeing

A greater effort should be made to provide emotional support for patients, as only 36% of respondents reported their doctor or healthcare professional was very helpful when they spoke about their concerns. For care to be compassionate, it must be delivered with respect, sensitivity, and appreciation of the person as an individual.

Taking part in clinical trials

One third of respondents (35%) reported they had been asked by a health professional to consider participating in a cancer clinical trial. Of these respondents, 70% agreed to participate in the cancer clinical trial. When asked about their overall experience of the cancer clinical trial, 65% of those who had participated reported they were very satisfied or satisfied, suggesting that 35% were not satisfied.

Patient feedback on management of small renal mass

If diagnosed with a small renal mass, willingness to participate in active surveillance was high, with two thirds of respondents (62%) willing to participate. Willingness to undergo a biopsy was also high, with 68% of respondents reporting they would be willing to have a biopsy of a small renal growth to help form a more precise diagnosis and treatment plan.

Surveillance preferences

Following surgery for kidney cancer, respondents were most likely to prefer surveillance to last less than two years (32%), but length of preferred surveillance varied significantly by country.

Genetic testing

Interestingly, 19% of respondents reported they met some or all of the criteria for genetic testing (diagnosed under 46 years old, family history of kidney cancer, or bilateral disease) but were not offered genetic testing. Further investigation into the circumstances of when genetic testing is offered would be beneficial to understand and mitigate any existing barriers.

Shared decision-making

Our data indicate that 48% of respondents were involved as much as they wanted to be in developing their treatment plan (Q13+), but unfortunately slightly more than half were not involved as much as they wanted to be. Compared with the previous 2018 and 2022 surveys, our data do not seem to indicate improvement in the area of shared decision making.

Key findings summary

Genetic testing

19% 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)

17% 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, **62%** of respondents 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)

68% 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):

32% would prefer to have regular imaging scans for less than 2 years

13% would prefer between 2 and 6 years

23% preferred more than 6 years

28% would make this decision based on their healthcare team's opinion

Shared decision-making

48% of respondents reported that they were definitely involved as much as they wanted to be in developing their treatment plan (Q13+), suggesting that slightly more than half were not involved as much as they wanted to be.

Understanding of diagnosis and treatment options

54% of respondents completely understood treatment options when planning their treatments (Q11_3+)

55% felt that treatment recommendations were completely understood when planning their treatments (Q11_4+)

42% 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

44% of respondents reported they did not understand adjuvant therapy (treatment aimed at reducing the chance of recurrence after surgery) (Q18_7+)

Emotional wellbeing

20% felt their sense of emotional wellbeing since their diagnosis has always been impacted by disease-related anxiety (Q24_2+)

28% reported fear of the cancer/growth coming back (recurrence) always impacts their sense of emotional wellbeing since their diagnosis (Q24_4+)

11% reported always feeling their sense of emotional wellbeing since their diagnosis being impacted by sadness or depression (Q24_5+)

Support from healthcare professionals

Only **36%** of respondents reported their doctor or healthcare professional was very helpful when they spoke about their concerns (Q27+)

Clinical trials

35% of respondents reported they had been asked by a health professional to consider participating in a cancer clinical trial (Q30)

70% agreed to participate in the cancer clinical trial (Q31)

65% reported they were very satisfied or satisfied with their overall experience of the cancer clinical trial (Q33)

Respondent profile

The 2022 IKCC Global Patient Survey received:

2,213 responses from **39** countries



Respondents comprised of:



1,655 Patients



547 Carers or caregivers



11 Undisclosed

Table 1. Q1 - Please describe your experience with kidney cancer and/or kidney growths by country of residence

Country	Total	I have been diagnosed with kidney cancer or a kidney growth	I am a carer or caregiver for a loved one who has been diagnosed with kidney cancer or a kidney growth	My loved one has died	Undisclosed
France	237	206	20	9	2
Republic of Korea	204	137	65	2	-
Canada	139	111	21	7	-
U.K. - England	128	106	18	4	-
Germany	125	109	13	3	-
Japan	119	104	13	1	1
United States of America	115	74	34	7	-
India	107	87	20	-	-
Mexico	106	49	32	24	1
South Africa	93	57	23	12	1
Italy	70	25	30	14	1
Netherlands	52	40	8	4	-
Sweden	52	44	6	2	-
Australia	27	21	6	-	-
Portugal	27	20	7	-	-
U.K. - Scotland	22	21	1	-	-
Spain	21	19	2	-	-
Brazil	18	13	4	1	-
Other	47	32	10	5	-
Unspecified ¹	504	380	82	37	5
Global	2,213	1,655	415	132	11

¹ 504 respondents did not select their country of residence.

Participant characteristics

Gender (Q5)



54%

Male



44%

Female

1% Prefer to self-describe
1% Do not wish to identify

Base: n=2207

Age in years (Q4)

< 18	1%
18 – 29	5%
30 – 45	22%
46 – 65	59%
66 – 80	12%
> 80	<1%

Base: n=2125

Current Stage of Kidney Cancer (Q16)

Localised	11%
Advanced or metastatic	47%
No evidence or cured	42%

Base: n=1780

Place of Diagnosis (Q7)



At a community, local or general hospital	35%
At my family doctor's office	17%
At an emergency department	15%
Other	11%
At a private clinic	10%
At a major cancer centre	5%
At a major cancer centre by a doctor who specialises in kidney cancer	5%
Don't know / Can't remember	1%

Base: n=2200

Kidney Cancer Subtype (Q2)

Clear Cell Renal Cell Carcinoma	58%
Papillary Renal Cell Carcinoma	21%
Chromophobe Renal Cell Carcinoma	4%
Other	3%
Don't know / Can't remember	3%
I was not told	2%
Unclassified Renal Cell Carcinoma	2%
Renal Medullary Carcinoma	1%
Benign growth	1%
Xp11 Translocation Type	1%
Transitional Cell Carcinoma (Urothelial Carcinoma)	1%
VHL (Von Hippel-Lindau syndrome)	1%
Wilms Tumour	1%
Collecting Duct Renal Cell Carcinoma (Bellini Duct)	0%
Renal Sarcoma (NOT Renal Cell Carcinoma with Sarcomatoid Appearance)	0%

Base: n=2190

Year of Diagnosis (Q6)



Prior to 2008	11%	2014 – 2016	13%
2008 – 2010	6%	2017 – 2019	24%
2011 – 2013	7%	2020 – Present	39%

Base: n=2110

Background

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.

The IKCC mission is to empower and represent the kidney cancer community through advocacy, awareness, information, and research with a vision to reduce the global burden of kidney cancer.

Picker was commissioned by the IKCC to run their 2022 biennial Global Patient Survey targeted at patients with kidney cancer or a kidney growth, their carers or caregivers, after successfully delivering the 2020 survey iteration.

Picker is an international charity dedicated to ensuring the highest quality health and social care for all, always. We conduct research to understand patient care needs and experiences, and 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.

Picker's expertise covers all stages of research from design, sampling and questionnaire development to execution, analysis, and reporting. Our Principles of Person Centred Care are an internationally recognised quality improvement framework that we use to produce actionable, insightful results. We empower our partners to act upon their results to deliver the highest quality person centred care for all, always.

Purpose of the global patient survey

The IKCC launched its first Global Patient Survey in 2018. This was the first-ever international survey of kidney cancer patient and carer experiences. This survey sought to improve collective understanding of patient experiences worldwide, look for best practice, and empower patient organisations with information they could act upon. In 2018, 1,983 patients and carers from 43 countries shared their views and experiences.

Following this successful launch, the IKCC have committed to run the Global Survey every two years, continuing to identify best practices whilst monitoring trends and exploring topics of special interest to Affiliate Organisations.

In 2020, 2,012 responses were received from patients and carer/caregivers in 41 countries. Now in its third iteration, response has continued to grow, with the 2022 survey achieving 2,213 patient and carer/caregiver responses across 39 countries globally.

This report outlines the methods and results from the 2022 Global Survey, administered by Picker on behalf of the IKCC.

Methodology

Questionnaire development

The 2022 survey underwent considerable review by the IKCC board, IKCC affiliate organisations and Picker. Furthermore, several changes were made to question wording and format for the 2022 survey to simplify language and streamline completion.

Two questions relating to biopsy practice were removed from the survey, along with the Patient Health Engagement scale section. Five new questions were introduced into the 2022 survey, three of which asked about willingness and preference regarding Active Surveillance and biopsy. One question was introduced as a follow up to enquire why respondents were dissatisfied with their clinical trial experience; this was an open ended question (Q34). Note that free text responses have not been included in this report. Furthermore, one question related to genetic testing.

The survey included demographic questions, including country of residence, age, gender, kidney cancer subtype, cancer stage at diagnosis, time since diagnosis and current cancer stage.

Before starting the survey, respondents were informed of the purpose of the programme; that completing the survey was voluntary and any feedback will be kept confidential; and how the results will be used. 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.

The English (UK) questions were translated into 14 languages, by an approved language translation service using native speakers to translate and proofread. The final translations were also reviewed by fluent IKCC members. The survey was published in the following languages:

- | | | |
|------------------------|-------------------|--------------|
| ○ Brazilian Portuguese | ○ French Canadian | ○ Korean |
| ○ Dutch | ○ German | ○ Polish |
| ○ English US | ○ Hindi | ○ Portuguese |
| ○ English UK | ○ Italian | ○ Spanish |
| ○ French | ○ Japanese | ○ Swedish |

A copy of the 2022 IKCC Global Survey can be found in Appendix 2.

Survey fieldwork

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

The survey was available online 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 social media and webpage.

Analysis and reporting

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.

Standard validation practices have been used in the survey tool and on the data collected, in this and associated reports to improve representativeness. Practices are outlined below:

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 who 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.

Data cleaning and validation

When the survey closed, the raw data were analysed and feedback that did not meet the inclusion criteria was removed. Criteria for inclusion involved 6 or more completed questions of which a minimum of three needed to be consecutive.

Data were also analysed for repeated entries through the open link and Bot Detection. This involved assessment of metadata including location data and Q_RecaptureScore². Any suspect data were analysed for potential ballot box stuffing through repeated entry.

433 responses were removed from the dataset as they did not meet the inclusion criteria.

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+.

Q8 - WHEN YOU WERE FIRST CORRECTLY DIAGNOSED, were you told what subtype of kidney cancer or kidney growth you had?			Q8+ - WHEN YOU WERE FIRST CORRECTLY DIAGNOSED, were you told what subtype of kidney cancer or kidney growth you had?		
Yes...	852	42%	Yes...	852	48%
No...	909	46%	No...	909	52%
Not sure...	243	12%			
<i>Total...</i>	<i>1,994</i>	<i>100%</i>	<i>Total...</i>	<i>1,751</i>	<i>100%</i>

Full frequency tables can be found in Appendix 3a and 3b.

Sub-group analysis

In this report, data have been considered as a whole and in a series of cross-tabulations to investigate patterns in care experiences by:

- country of residence
- cancer stage at diagnosis
- cancer stage at time of response
- age group
- gender
- respondent subtype (patient/caregiver)
- level of physical activity

Please note, for any sub-group analysis, data are not reported on any groups with fewer than 30 respondents. This is to protect respondent confidentiality and because data can be misleading and unrepresentative from low numbers of respondents. Furthermore, it is important to note that statistical testing has not been conducted to understand whether differences in responses between sub-groups are statistically significant or not.

A country-specific report has been written for the 10 countries with the highest responses (93 and above). These are available as separate documents and include:

² Q_RecaptchaScore is an automated feature for Bot Detection in the online survey platform Qualtrics, which was used for this programme. Source Technology is from Google’s invisible reCaptcha. A score of greater than or equal to 0.5 indicates that the respondent is likely a human as opposed to an automated bot.

- France
- Republic of Korea
- Canada
- United Kingdom - England
- Germany
- Japan
- United States of America
- India
- Mexico
- South Africa

Data presentation

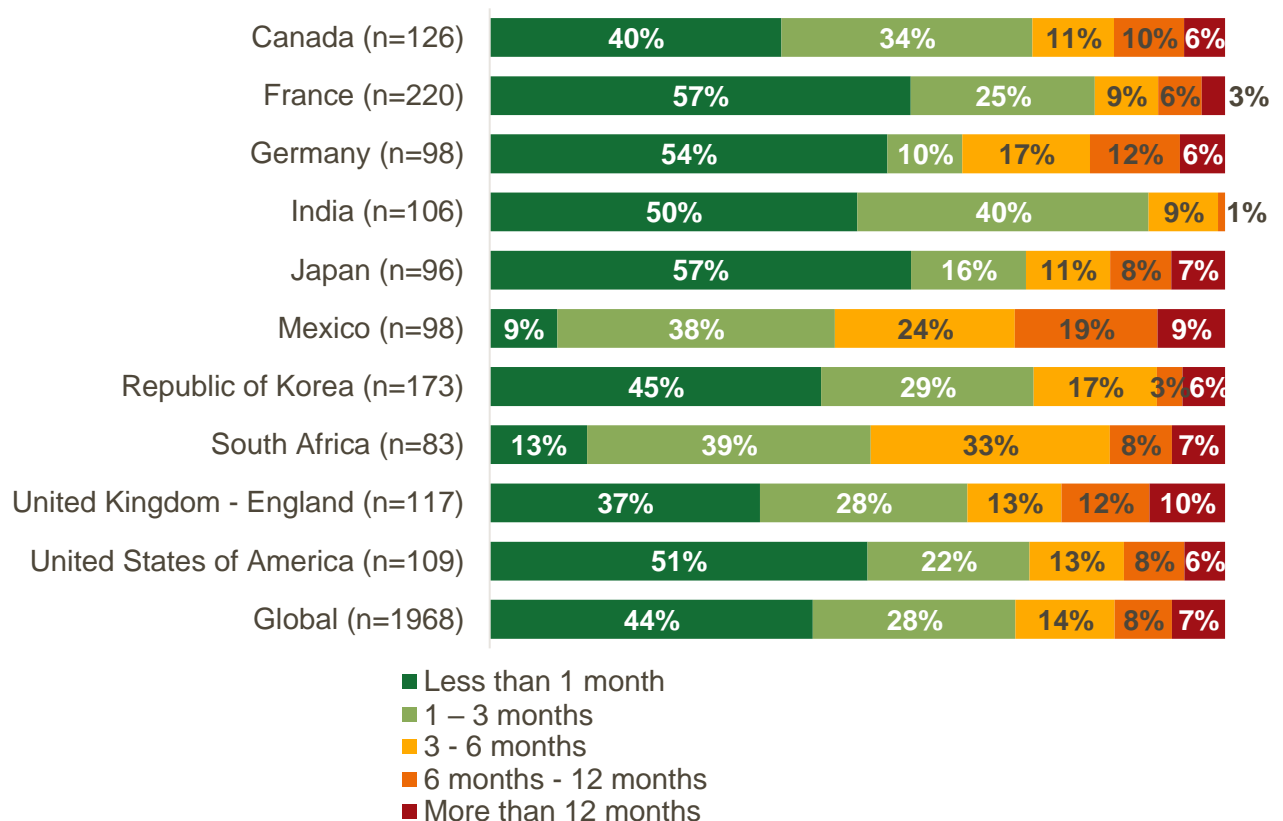
Throughout this report, percentages have been rounded to 0 decimal places. This means that sometimes the total for a single-response question can be just below or above 100%.

Diagnosis

Time to correct diagnosis

Access to the right services at the right time is essential for high quality care that meets individual's needs. Fast, easy access is important for both routine care and unplanned crises. Globally, 71% of respondents (n=1,407) waited less than 3 months from the time they first thought something might be wrong to being diagnosed. See Figure 1 for full breakdown of results by country.

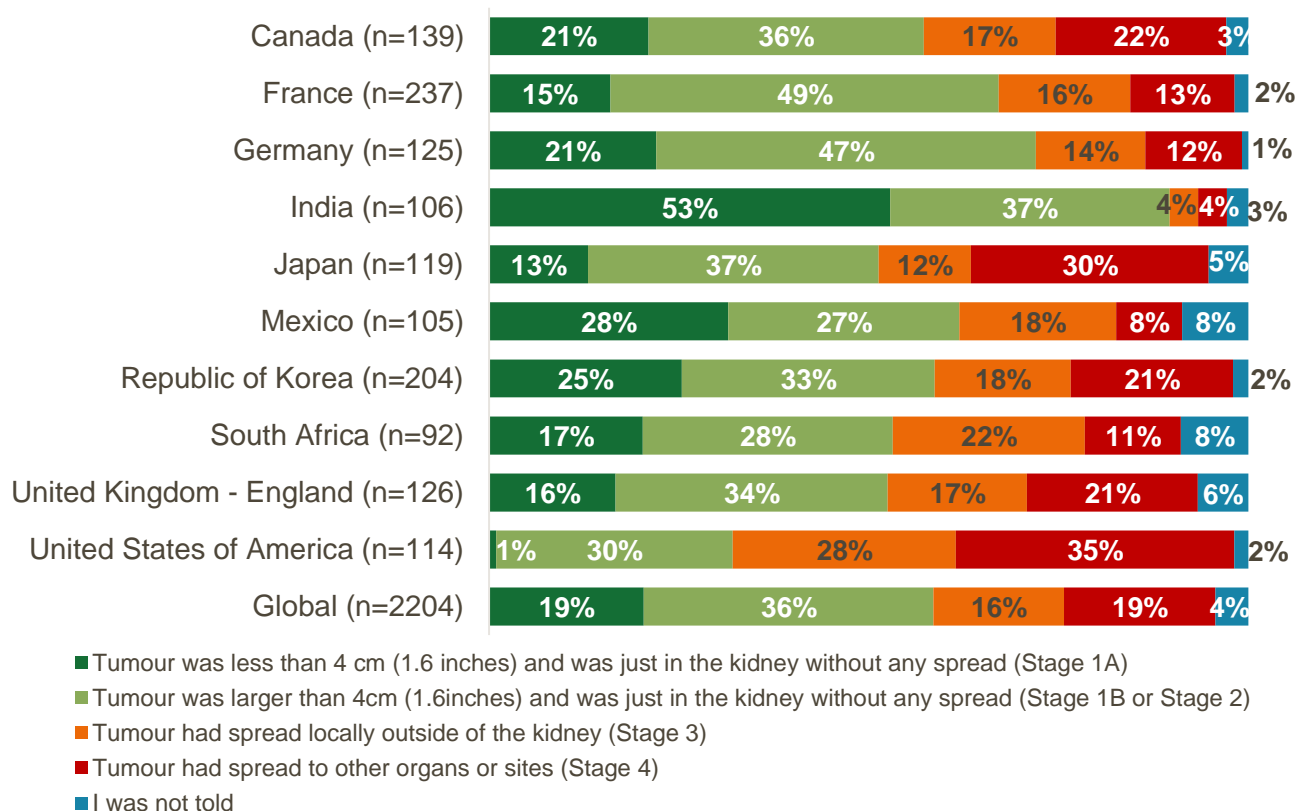
Figure 1. Q10+ - How long was it from the time you first thought something might be wrong with you to being diagnosed? By country of residence



Stage and subtype of kidney tumour(s) at diagnosis

Stage of kidney tumours(s) at diagnosis varied widely by country of residence (Figure 2). India had the highest proportion of respondents diagnosed at Stage 1A (53%, n=56), while the USA had the highest proportion of respondents diagnosed at Stage 4 (35%, n=40).

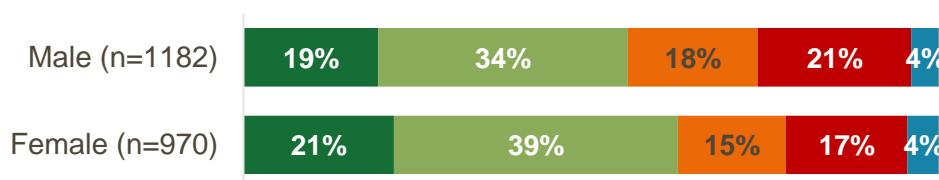
Figure 2. Q9 - At what stage was the kidney tumour when you were FIRST DIAGNOSED? By country of residence



Please note the 'don't know' and 'other' responses have been excluded from this graph and percentages do not sum to 100%.

Analysis by gender reveals males (39%, n=461) were more likely to be diagnosed at the advanced or metastatic stages (Stage 3 or 4) than females (32%, n=307) (Figure 3).

Figure 3. Q9 - At what stage was the kidney tumour when you were FIRST DIAGNOSED? by gender



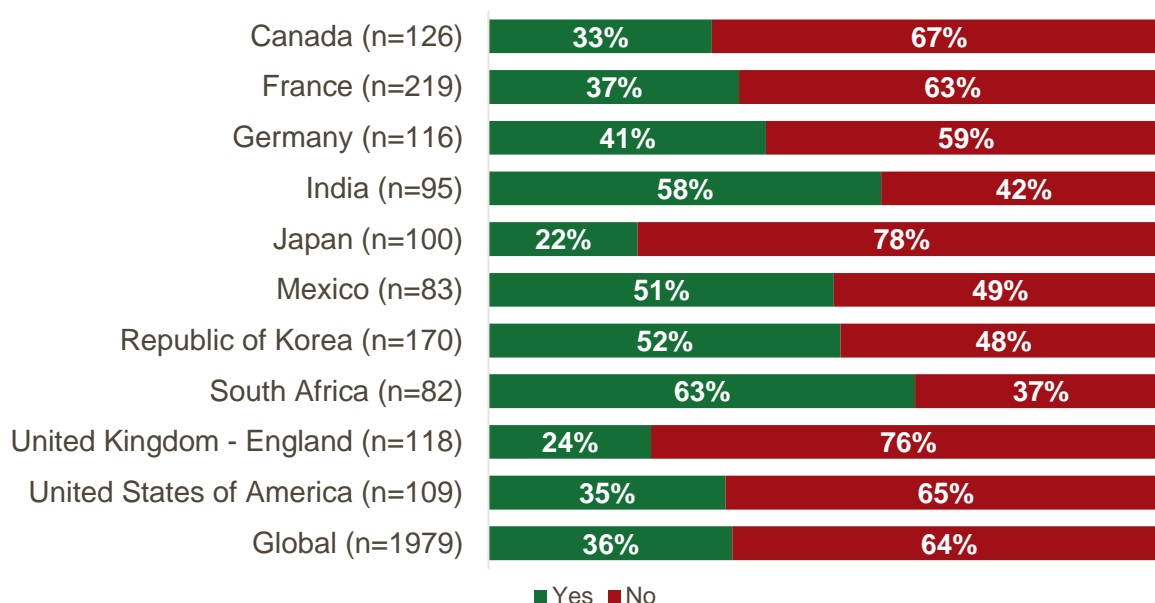
- Tumour was less than 4 cm (1.6 inches) and was just in the kidney without any spread (Stage 1A)
- Tumour was larger than 4cm (1.6inches) and was just in the kidney without any spread (Stage 1B or Stage 2)
- Tumour had spread locally outside of the kidney (Stage 3)
- Tumour had spread to other organs or sites (Stage 4)
- I was not told

Please note the 'don't know' and 'other' responses have been excluded from this graph and percentages do not sum to 100%.

One third of respondents globally (36%, n=717) were told what sub-type of kidney cancer or kidney growth they had when they were first diagnosed, whereas 64% (n=1,262) were not told this information (to be told sub-type information.

). South Africa (63%, n=52) and India (58%, n=55) respondents were most likely to report they were told this information, while respondents from Japan (22%, n=22) and England (24%, n=28) were least likely to be told sub-type information.

Figure 4. Q8+ - WHEN YOU WERE FIRST DIAGNOSED, were you told what sub-type of kidney cancer or kidney growth you had? By country of residence



Knowledge when planning treatments

People using healthcare services should receive reliable, high quality and accessible information at every stage in their journey. This information enables patients to make informed decisions when planning treatments. Respondents were asked to what extent certain aspects were explained to them when planning their treatments.

Understanding of treatment options

More than half of respondents said treatment recommendations (55%, n=1078) and treatment options (54%, n=1079) were completely explained. In contrast, only 28% (n=540) said the likelihood of surviving their cancer beyond five years was completely explained when planning treatments:

- Treatment recommendations completely explained: 55%, n=1078 (Figure 8)
- Treatment options completely explained: 54%, n=1079 (Figure 7)
- Stage of cancer completely explained: 48%, n=990 (Figure 5)
- Risk of recurrence completely explained: 34%, n=654 (Figure 9)
- Sub-type of cancer completely explained: 33%, n=617 (
- Understanding of sub-type

Understanding of kidney cancer subtype can be critical to making evidence-based decisions regarding treatment. Respondents from South Africa were most likely to report that sub-type was completely explained (58%, n=48). Respondents from Germany (45%, n=50) and England (44%, n=50) were most likely to report cancer sub-type was not explained (Figure 6).

- Figure 6)
- Likelihood of surviving your cancer beyond five years completely explained: 28%, n=540 (Understanding of likelihood of survival

In many countries, patients reported that the likelihood of their survival beyond 5 years was not explained to them (Figure 10Figure 10).

- Figure 10)

Results varied widely by country of residence. This presents a learning opportunity for affiliate organisations to share ways of working to ensure patients, carers and caregivers are fully informed at the beginning of their health journey.

Understanding of stage

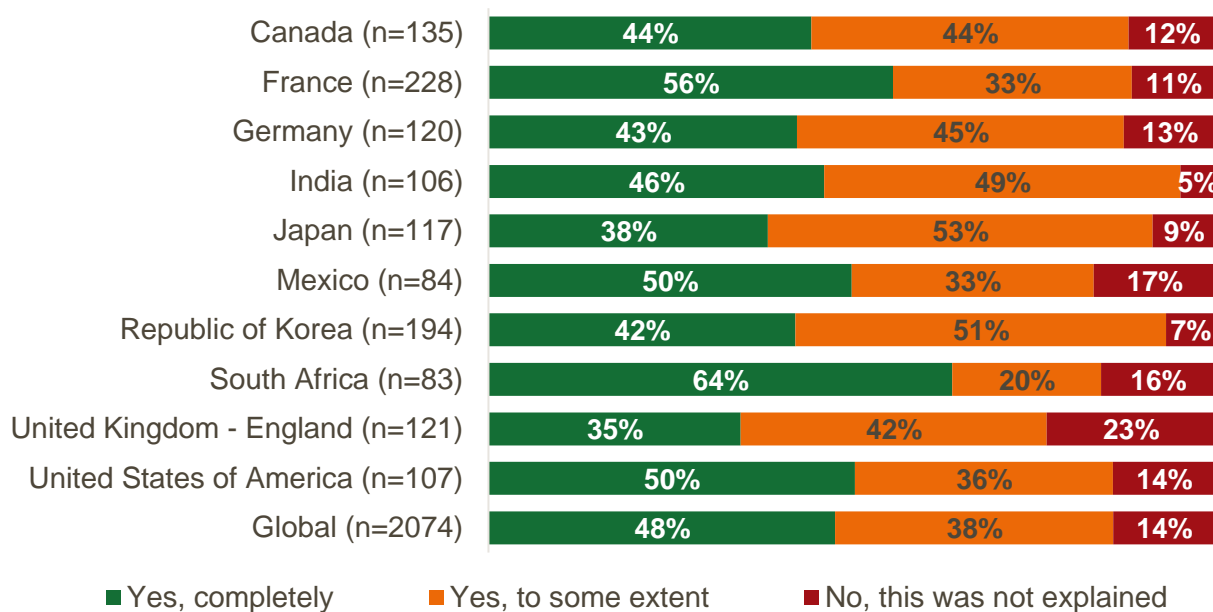
South Africa respondents were most likely to report that stage of cancer (64%, n=53) (Figure 5) and sub-type of cancer (58%, n=48) (

Understanding of sub-type

Understanding of kidney cancer subtype can be critical to making evidence-based decisions regarding treatment. Respondents from South Africa were most likely to report that sub-type was completely explained (58%, n=48). Respondents from Germany (45%, n=50) and England (44%, n=50) were most likely to report cancer sub-type was not explained (Figure 6).

Figure 6) were completely explained in a way that was understood when planning treatments, compared with other countries.

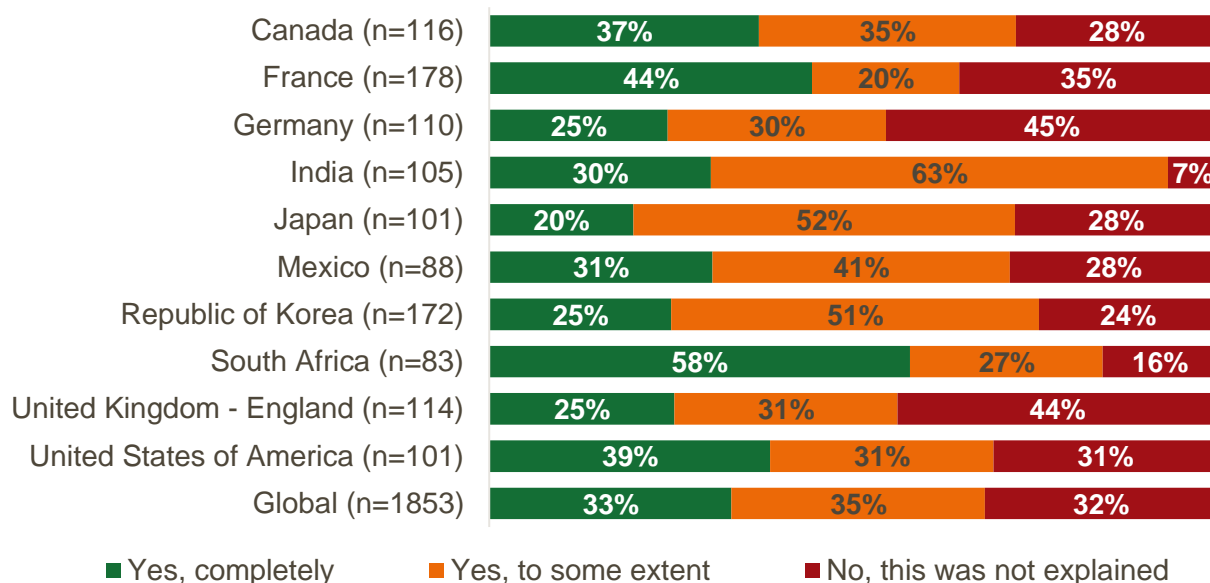
Figure 5. Q11_1+ - When planning your treatments, were the following explained in a way you could understand? – Stage of cancer by country of residence



Understanding of sub-type

Understanding of kidney cancer subtype can be critical to making evidence-based decisions regarding treatment. Respondents from South Africa were most likely to report that sub-type was completely explained (58%, n=48). Respondents from Germany (45%, n=50) and England (44%, n=50) were most likely to report cancer sub-type was not explained (Figure 6).

Figure 6. Q11_2+ - When planning your treatments, were the following explained in a way you could understand? – Sub-type of cancer by country of residence



Understanding of treatment options

Respondents in France were most likely to report treatment options (71%, n=156) (Figure 7) and treatment recommendations (71%, n=149) (Figure 8) were completely explained in a way that was understood when planning treatments relative to other countries. Conversely, respondents in Mexico were most likely to report treatment options (24%, n=21) and treatment recommendations (25%, n=21) were not explained.

Figure 7. Q11_3+ - When planning your treatments, were the following explained in a way you could understand? – Treatment options by country of residence

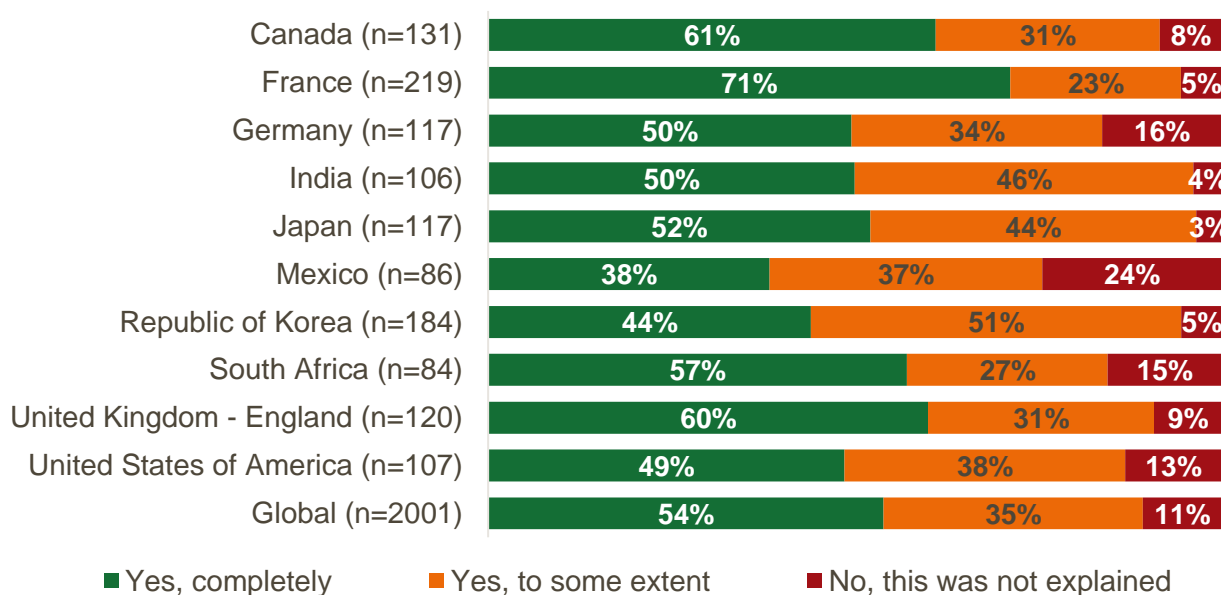
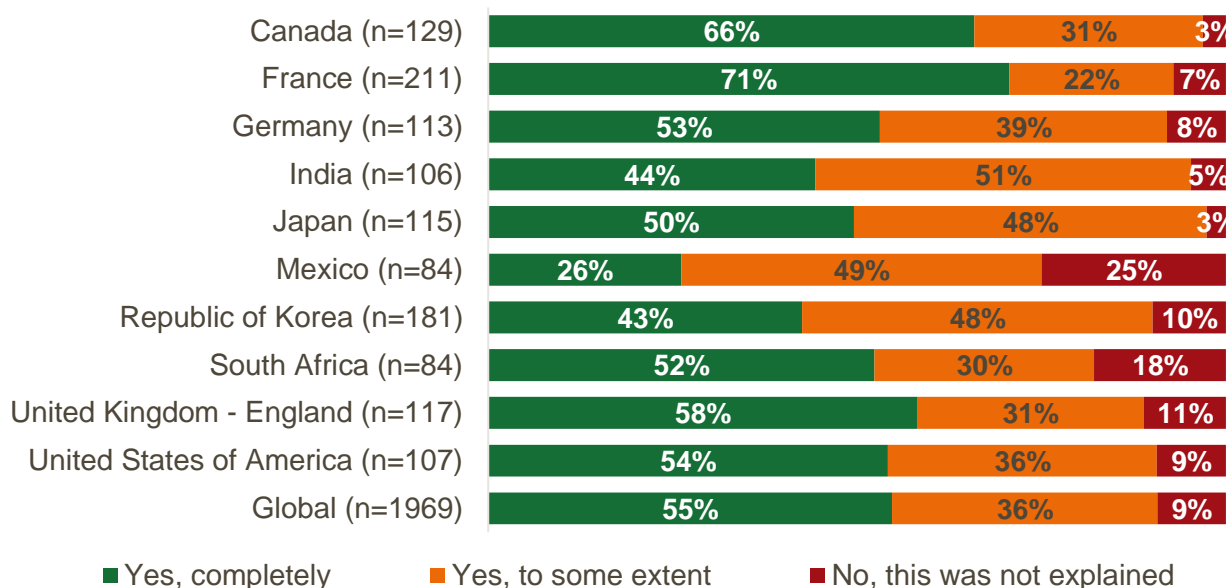


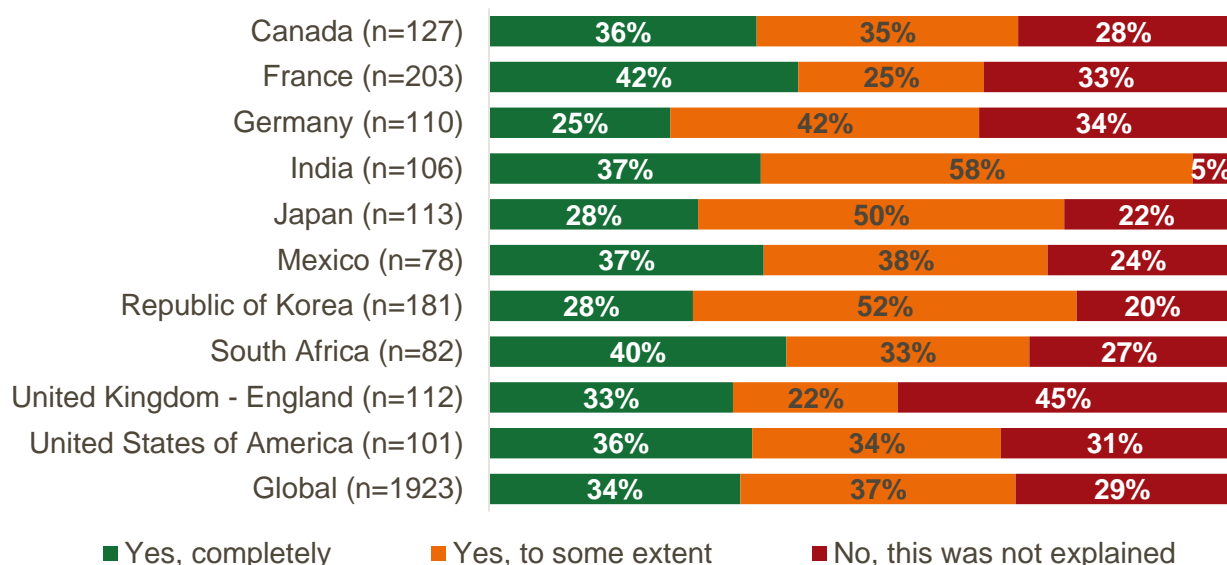
Figure 8. Q11_4+ - When planning your treatments, were the following explained in a way you could understand? – Treatment recommendations by country of residence



Understanding risk of recurrence

Compared with other countries, the risk of recurrence was most likely to be completely explained in France (42%, n=85) and South Africa (40%, n=33) (Figure 9), while the likelihood of surviving cancer beyond 5 years was most likely to be completely explained in South Africa (46%, n=38).

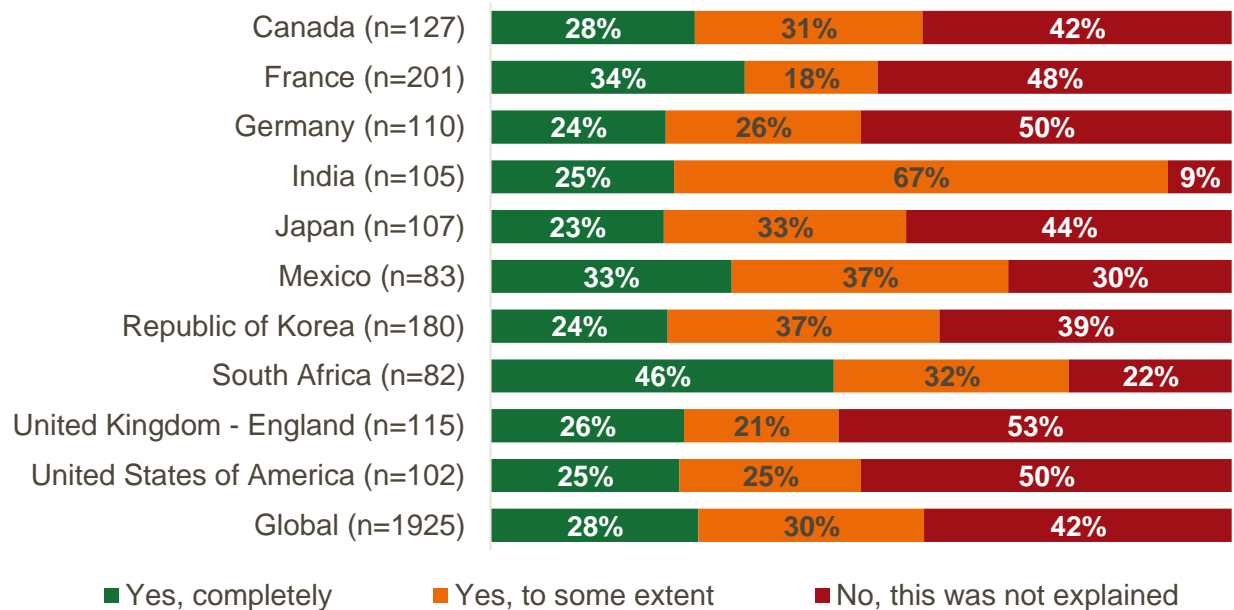
Figure 9. Q11_5+ - When planning your treatments, were the following explained in a way you could understand? – Risk of recurrence by country of residence



Understanding of likelihood of survival

In many countries, patients reported that the likelihood of their survival beyond 5 years was not explained to them (Figure 10).

Figure 10. Q11_6+ - When planning your treatments, were the following explained in a way you could understand? – Likelihood of surviving your cancer beyond five years by country of residence



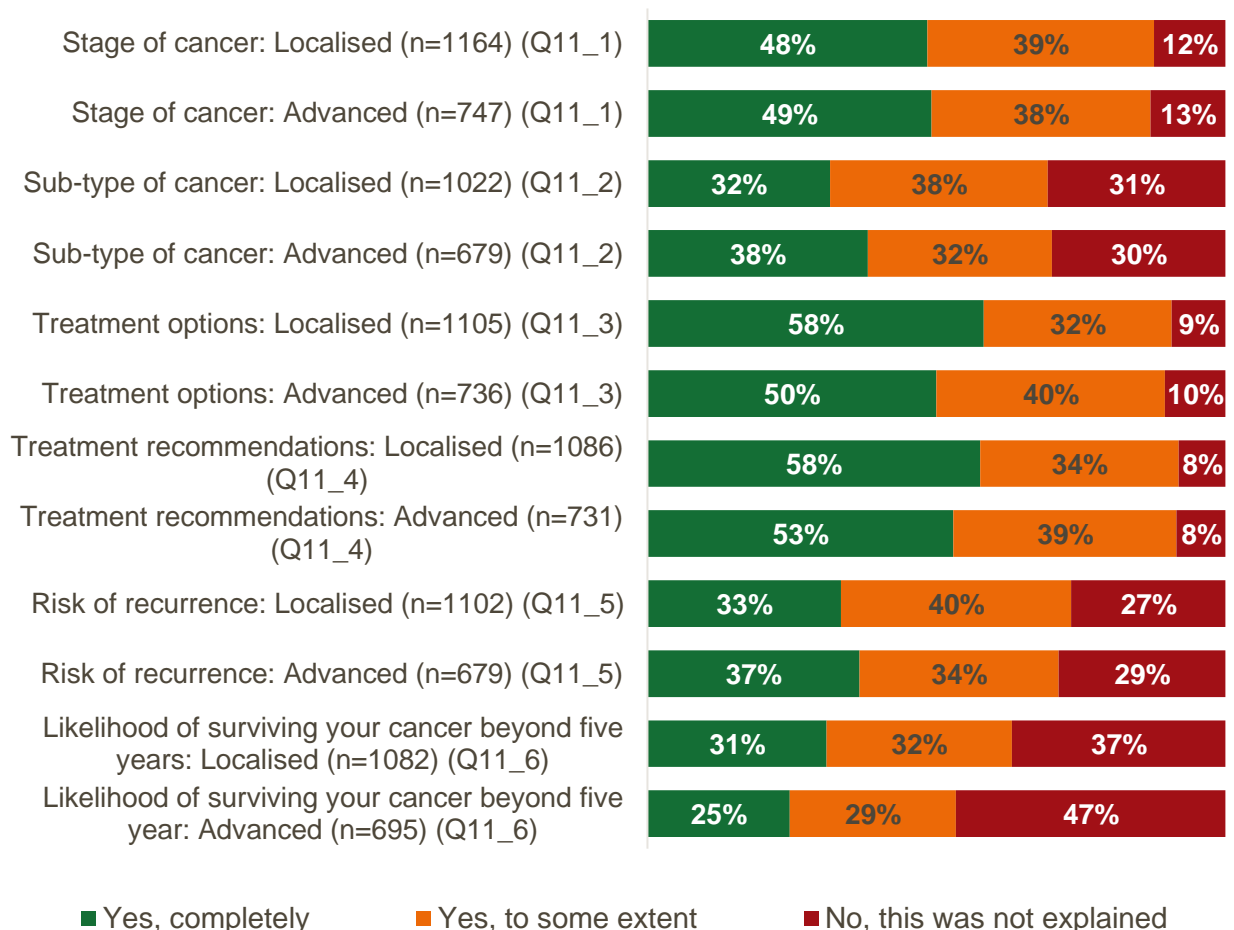
Understanding by stage of disease

There are notable differences in reported experience between those who were diagnosed at localised and advanced stages of cancer (Figure 11).

Respondents diagnosed at a localised stage reported a more positive experience of receiving complete explanations of treatment options (58%, n=643) and treatment recommendations (58%, n=625), than those diagnosed at an advanced stage (50%, n=368; 53%, n=387 respectively).

Almost half of respondents diagnosed at an advanced stage of cancer (47%, n=324) said the likelihood of surviving cancer beyond 5 years was not explained to them when planning treatments. This is compared with 37% (n=400) of respondents diagnosed at a localised stage.

Figure 11. Q11_1+ to Q11_6+ - When planning your treatments, were the following explained in a way you could understand? by stage of cancer at diagnosis



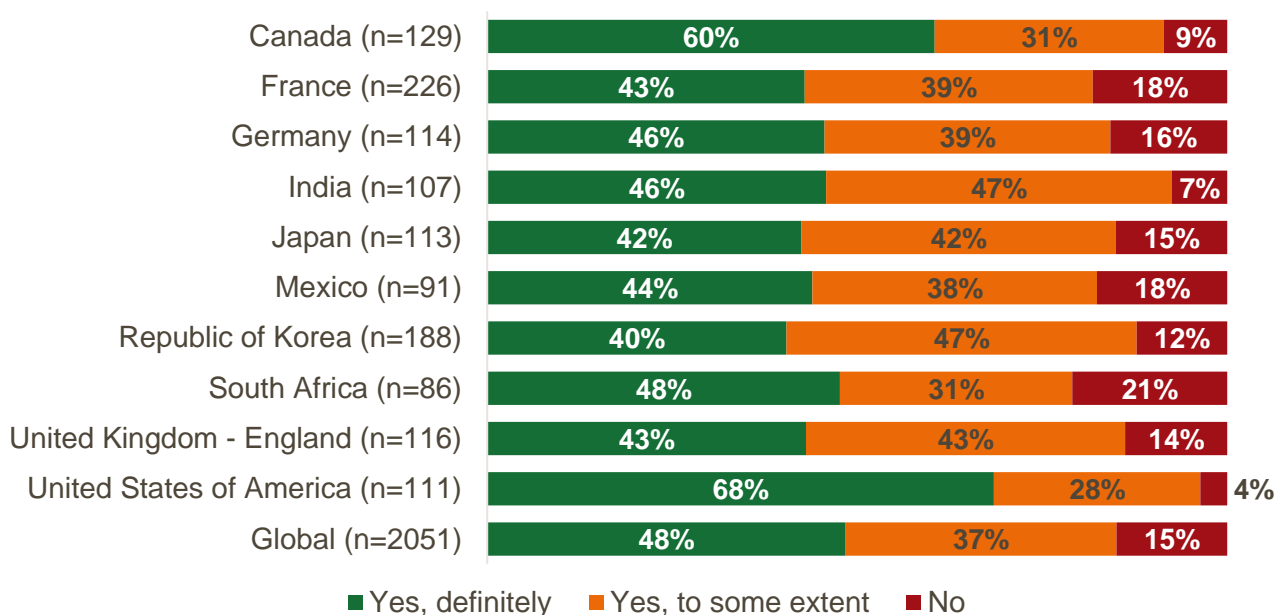
Developing a treatment plan and shared decision-making

Patients, carers and caregivers have the right to be involved in decisions about the patient's health and care. Healthcare providers should work with people in equal, reciprocal partnerships, and should respect people's choices and preference when developing a treatment plan.

Involvement in developing a treatment plan/shared decision making

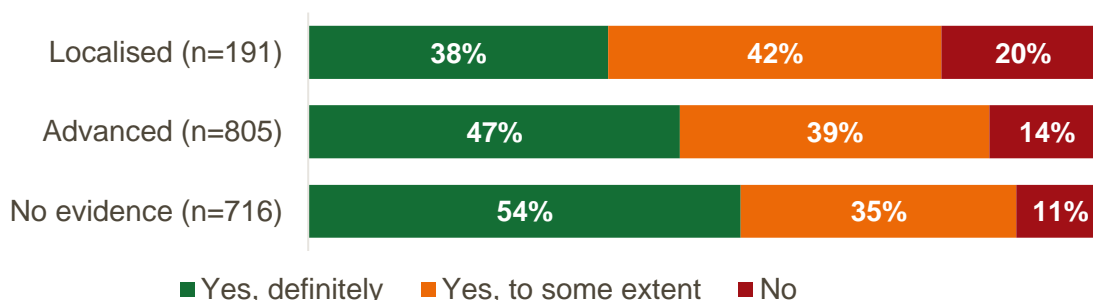
Globally, 48% of respondents (n=992) reported they were definitely involved as much as they wanted to be in decisions about their treatment plan (Figure 12). Respondents in the USA (68%, n=76) and Canada (60%, n=78) were most likely to report being definitely involved as much as they wanted to be, compared with respondents from other countries. South Africa had the highest proportion of respondents who responded no to this question (21%, n=18).

Figure 12. Q13+ - Were you involved as much as you wanted to be in decisions about your treatment plan? By country of residence



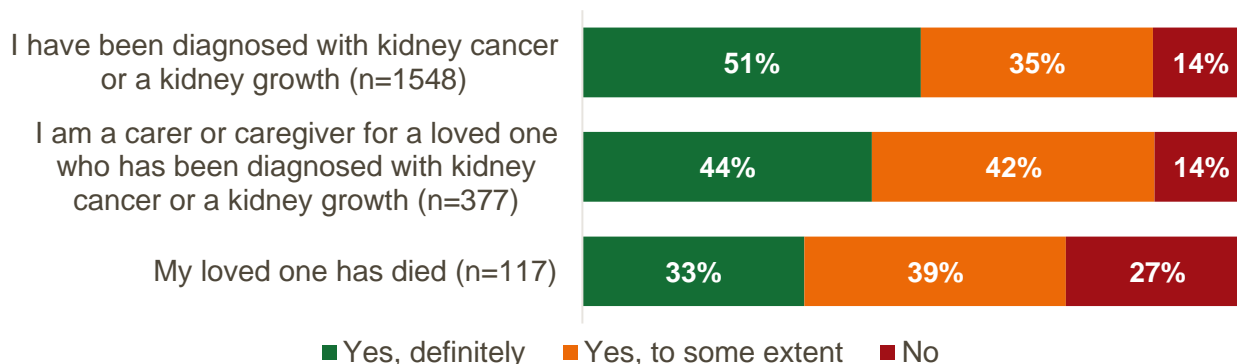
Sentiment towards involvement differed according to current stage of cancer. More than half of respondents with no current evidence of cancer (54%, n=389) were definitely involved as much as they wanted to be in decisions about their treatment plan. This is compared with 47% (n=376) of those currently at an advanced cancer stage, and 38% (n=72) of those currently at a localised stage (Figure 13).

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



Response to level of involvement in decision-making varied by respondent type (Figure 14). Half of respondents who were diagnosed with kidney cancer or a kidney growth (51%, n=787) were definitely involved as much as they wanted to be in decisions about their treatment plan. This is compared with 44% (n=164) of carers and caregivers for a loved one, and 33% (n=39) whose loved one has died.

Figure 14. Q13+ - Were you involved as much as you wanted to be in decisions about your treatment plan? By respondent type



Sources of help with shared decision making

Globally, partners or spouses was the most cited source of help sought by respondents for making decisions about treatment plans (47%, n=996), while one fifth cited their family doctor as a source of help (21%, n=439) (Table 2).

Respondents from India (39%, n=42) and the Republic of Korea (36%, n=69) were more likely to seek support from a patient organisation or support group than any of the other countries. French residents were most likely to report they made decisions about their treatment plan alone (31%, n=72).

Table 2. Q14 - Who or what else helped you make decisions about your treatment plan?
[multiple choice] by country of residence

	Global	Canada	France	Germany	India	Japan	Mexico	Rep. of Korea	South Africa	U.K. England	USA
Base (n=)	2120	132	231	120	107	118	98	194	91	123	112
My partner / spouse	47%	73%	39%	50%	53%	42%	32%	42%	18%	49%	69%
My parents	11%	4%	4%	3%	50%	13%	43%	6%	3%	3%	9%
My children	16%	11%	8%	13%	40%	8%	23%	19%	12%	9%	11%
My friends / other family members	16%	8%	11%	10%	61%	11%	24%	16%	25%	10%	13%
My family doctor	21%	25%	20%	23%	54%	34%	29%	10%	37%	5%	15%
A patient organisation or support group	15%	17%	4%	15%	39%	14%	6%	36%	5%	13%	13%
Online resources	14%	16%	8%	12%	29%	25%	4%	20%	2%	12%	22%
It was my decision alone	17%	11%	31%	24%	0%	19%	4%	11%	7%	20%	8%
My personal financial situation	4%	2%	1%	0%	8%	5%	6%	9%	18%	0%	4%
Don't know / Can't remember	2%	1%	2%	3%	0%	2%	7%	0%	2%	5%	1%
Other	9%	11%	16%	18%	0%	4%	1%	2%	1%	14%	7%

Kidney Cancer care and treatment

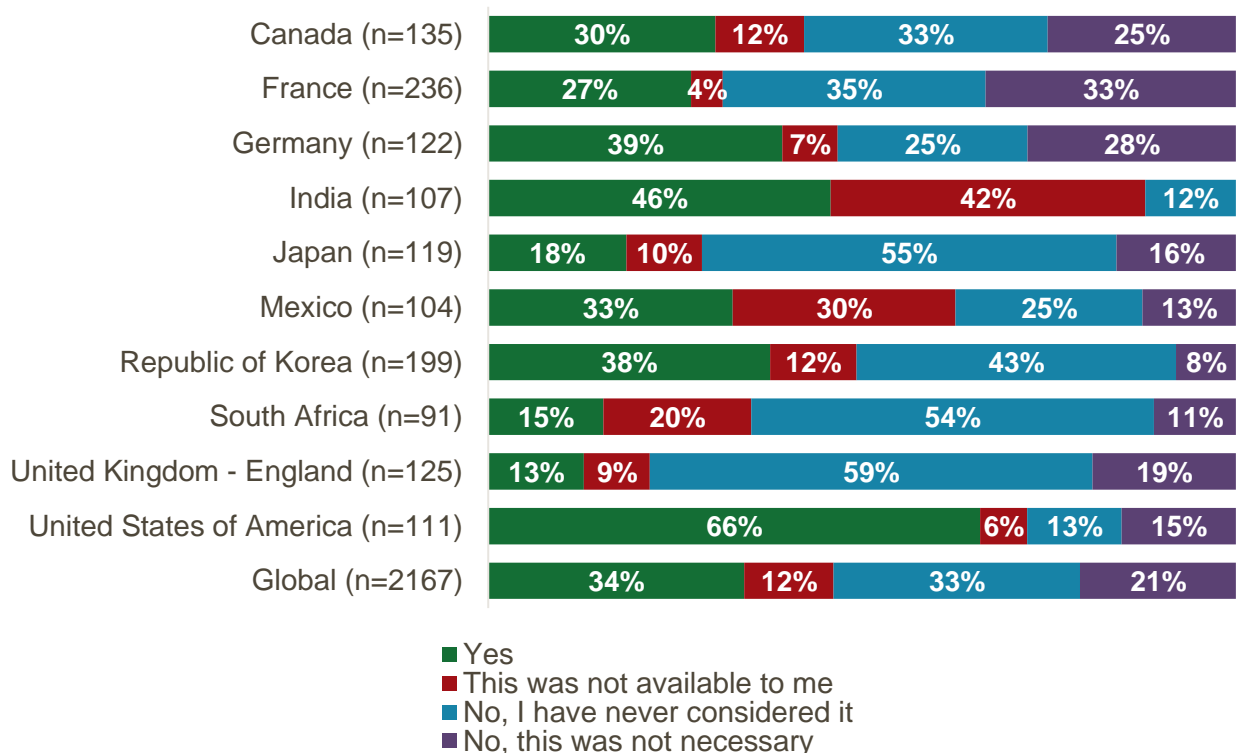
Getting a second opinion

Globally, one third of respondents (34%, n=742) sought a second opinion about their kidney cancer, 12% (n=259) said a second opinion was not available to them, 33% (n=714) never considered seeking a second opinion and 21% (n=452) said this was not necessary (Figure 15).

The USA reported the highest proportion of respondents seeking a second opinion (66%, n=73), followed by India (46%, n=49).

England (13%, n=16) had the lowest proportion of respondents who sought a second opinion, and the highest proportion who said they had never considered doing so (59%, n=74).

Figure 15. Q12 - Did you ever seek a second opinion about your kidney cancer? by country of residence



As shown in Figure 16, as age increases, the proportion of respondents who sought a second opinion decreases. Globally, 40% (n=20) of those aged 18 to 29 reported seeking a second opinion, compared with just 25% (n=13) of those over 80.

Figure 16. Q12 - Did you ever seek a second opinion about your kidney cancer? by age group

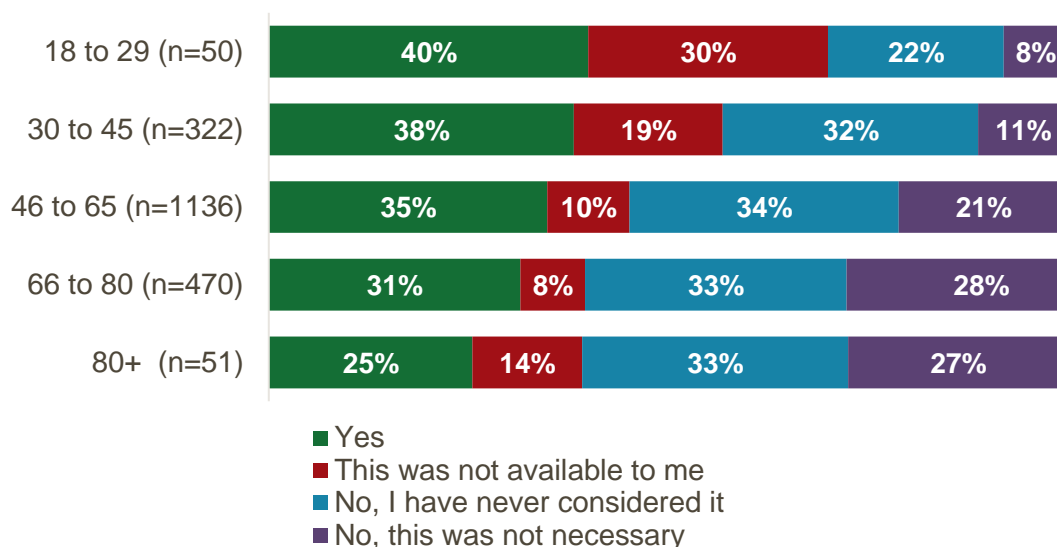


Table 3 indicates that respondents who had cancer at an advanced stage were more likely to report seeking a second opinion. 38% (n=294) of those *diagnosed* at an advanced stage sought a second opinion, compared with 33% (n=395) of those diagnosed at a localised stage. 39% (n=325) of respondents *currently* at an advanced stage reported seeking a second opinion, compared with 34% (n=68) at a localised stage and 30% (n=225) of those with no current evidence of cancer.

Table 3. Q12 - Did you ever seek a second opinion about your kidney cancer? by stage of cancer at diagnosis and current stage of cancer

	Cancer stage at diagnosis		Current stage of cancer		
	Localised	Advanced	Localised	Advanced	No evidence
Base (n=)	1202	776	201	828	747
Yes	33%	38%	34%	39%	30%
This was not available to me	13%	10%	22%	9%	13%
No, I have never considered it	34%	31%	31%	31%	35%
No, this was not necessary	21%	21%	13%	20%	22%

Barriers to treatment

Less than half of respondents globally (46%, n=953) experienced no barriers to their treatment choices for their kidney cancer or kidney growth. The most commonly experienced barriers were the cost of treatment (20%, n=420) and waiting time to treatment (18%, n=379).

Figures in red in

Table 4 indicate most referenced barrier to treatment choices for each country. Cost of treatment (the most common barrier globally) was the most cited barrier in India (82%, n=88), followed by South Africa (56%, n=50), Republic of Korea (44%, n=84), Mexico (39%, n=40) and Japan (37%, n=43). Residents in France (83%, n=190) and Germany (71%, n=84) were most likely to report they experienced no barriers to their treatment choices. Conversely, 100% (n=107) of residents in India cited at least one barrier to their treatment choices.

Table 4. Q15 - Which barriers (if any) have you experienced that affected your treatment choices for your kidney cancer or kidney growth? [multiple choice] by country of residence

	Global	Canada	France	Germany	India	Japan	Mexico	Rep. of Korea	South Africa	U.K. England	USA
Base (n=)	2085	125	228	119	107	117	102	190	90	117	109
Cost of treatment	20%	7%	0%	2%	82%	37%	39%	44%	56%	1%	8%
Lack of access to treatment centre/ prohibitive travel	12%	6%	2%	3%	35%	6%	27%	22%	28%	4%	6%
Language/ inability to understand the treatment	4%	0%	0%	1%	20%	2%	12%	2%	29%	0%	2%
Lack of access to the most up-to-date treatment or equipment	10%	9%	2%	3%	19%	5%	22%	11%	26%	8%	6%
Wait time to treatment was an issue for me	18%	16%	2%	8%	50%	18%	16%	25%	50%	12%	9%
Lack of personal support	10%	5%	3%	8%	19%	15%	13%	7%	6%	14%	5%
No speciality doctor locally	9%	10%	2%	7%	15%	3%	12%	11%	2%	12%	10%
Difficulty managing my carer/caregiver role (child, parent, disabled person) while in treatment	7%	6%	2%	3%	20%	12%	6%	14%	4%	3%	4%
Fear of discrimination if my employer/ friends/ family knew about my disease	5%	2%	1%	1%	14%	10%	8%	7%	4%	3%	3%
No available treatments	4%	2%	2%	0%	1%	2%	11%	2%	2%	0%	3%
Other barrier not mentioned above	7%	9%	5%	8%	0%	13%	1%	5%	4%	12%	8%
<i>Experienced no barriers</i>	46%	63%	83%	71%	0%	32%	13%	19%	9%	65%	59%

Figures in red in Table 5 indicate the most referenced barrier for each age group. Cost of treatment was the most cited barrier to treatment choices for younger age groups 18 to 29 (49%, n=24), 30 to 45 (29%, n=90), and 46 to 65 (21%, n=227). Lack of access to treatment centre/prohibitive travel was the most common barrier to affect respondents aged over 80 (21%, n=10). Just 10% (n=5) of 18 to 29-year-olds reported experiencing no barriers to their treatment choices – this was substantially lower than reported by other age groups.

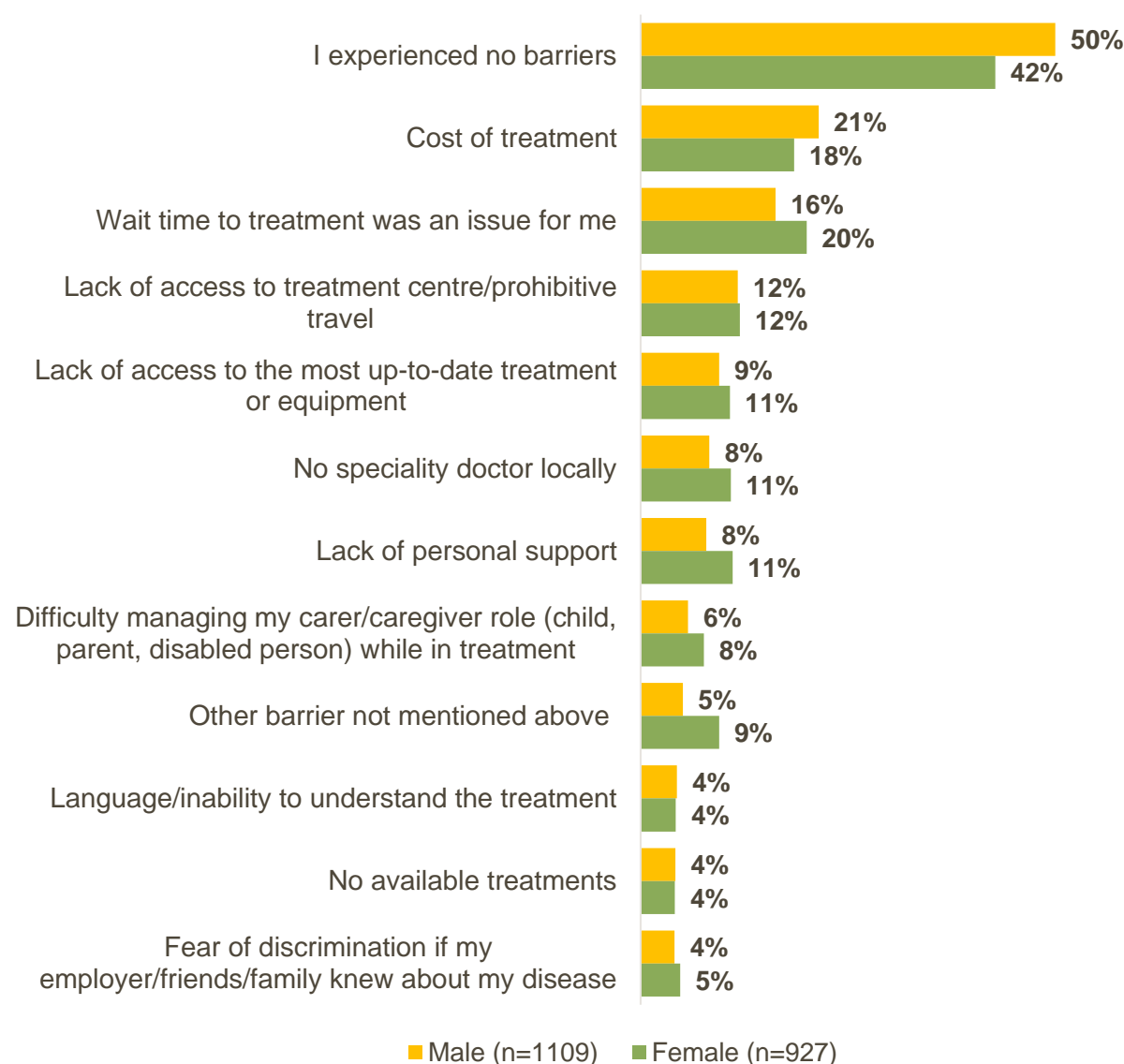
Table 5. Q15 - Which barriers (if any) have you experienced that affected your treatment choices for your kidney cancer or kidney growth? [multiple choice] by age group

	18-29	30-45	46-65	66-80	80+
Base (n=)	49	313	1097	451	47
Cost of treatment	49%	29%	21%	10%	9%
Lack of access to treatment centre/prohibitive travel	24%	21%	10%	7%	21%
Language/inability to understand the treatment	8%	12%	3%	2%	4%
Lack of access to the most up-to-date treatment or equipment	18%	13%	9%	9%	6%
Wait time to treatment was an issue for me	18%	26%	19%	11%	17%
Lack of personal support	12%	13%	9%	8%	13%
No speciality doctor locally	12%	12%	8%	10%	9%
Difficulty managing my carer/caregiver role (child, parent, disabled person) while in treatment	6%	13%	5%	4%	4%
Fear of discrimination if my employer/friends/family knew about my disease	2%	8%	5%	2%	2%
No available treatments	10%	4%	4%	4%	6%
Other barrier not mentioned above	2%	5%	8%	7%	6%
<i>Experienced no barriers</i>	10%	29%	47%	60%	49%

Figure 17 highlights variances in barriers to treatment choices by gender. Males (50%, n=550) were more likely to report they experienced no barriers to their treatment choices than females (42%, n=393).

The most commonly cited barrier for males was cost of treatment (21%, n=236), while the most commonly cited barrier for females was wait time to treatment being an issue for them (20%, n=184).

Figure 17. Q15 - Which barriers (if any) have you experienced that affected your treatment choices for your kidney cancer or kidney growth? [multiple choice] by gender



Figures in red in Table 6 indicate the most referenced barrier to treatment choices by stage of cancer at diagnosis and by current stage of cancer. Experience of barriers to treatment choices was similar for respondents regardless of whether they were diagnosed at the localised or advanced stage, with 47% of each group (n=538; n=350 respectively) experiencing no barriers.

When looking at current stage of cancer, just 19% (n=37) of respondents currently in a localised stage reported experiencing no barriers to treatment choices, compared with 50% (n=409) currently in an advanced stage and 52% (n=377) of those with no current evidence of cancer.

Cost of treatment was cited as the most common barrier for all stages, with the exception of respondents with no current evidence of cancer, who reported wait time to treatment as their most commonly experienced barrier (17%, n=124).

Table 6. Q15 - Which barriers (if any) have you experienced that affected your treatment choices for your kidney cancer or kidney growth? [multiple choice] by stage of cancer at diagnosis and current stage of cancer

	Cancer stage at diagnosis		Current stage of cancer		
	Localised	Advanced	Localised	Advanced	No evidence
Base (n=)	1154	751	200	819	728
Cost of treatment	21%	19%	44%	18%	15%
Lack of access to treatment centre/prohibitive travel	12%	12%	22%	12%	11%
Language/inability to understand the treatment	5%	4%	13%	3%	3%
Lack of access to the most up-to-date treatment or equipment	9%	11%	15%	11%	7%
Wait time to treatment was an issue for me	19%	17%	34%	15%	17%
Lack of personal support	10%	9%	9%	9%	10%
No speciality doctor locally	8%	11%	11%	10%	8%
Difficulty managing my carer/caregiver role (child, parent, disabled person) while in treatment	7%	6%	10%	7%	6%
Fear of discrimination if my employer/friends/family knew about my disease	5%	5%	6%	5%	4%
No available treatments	3%	5%	5%	4%	2%
Other barrier not mentioned above	6%	7%	4%	6%	7%
<i>Experienced no barriers</i>	47%	47%	19%	50%	52%

Care and treatment today

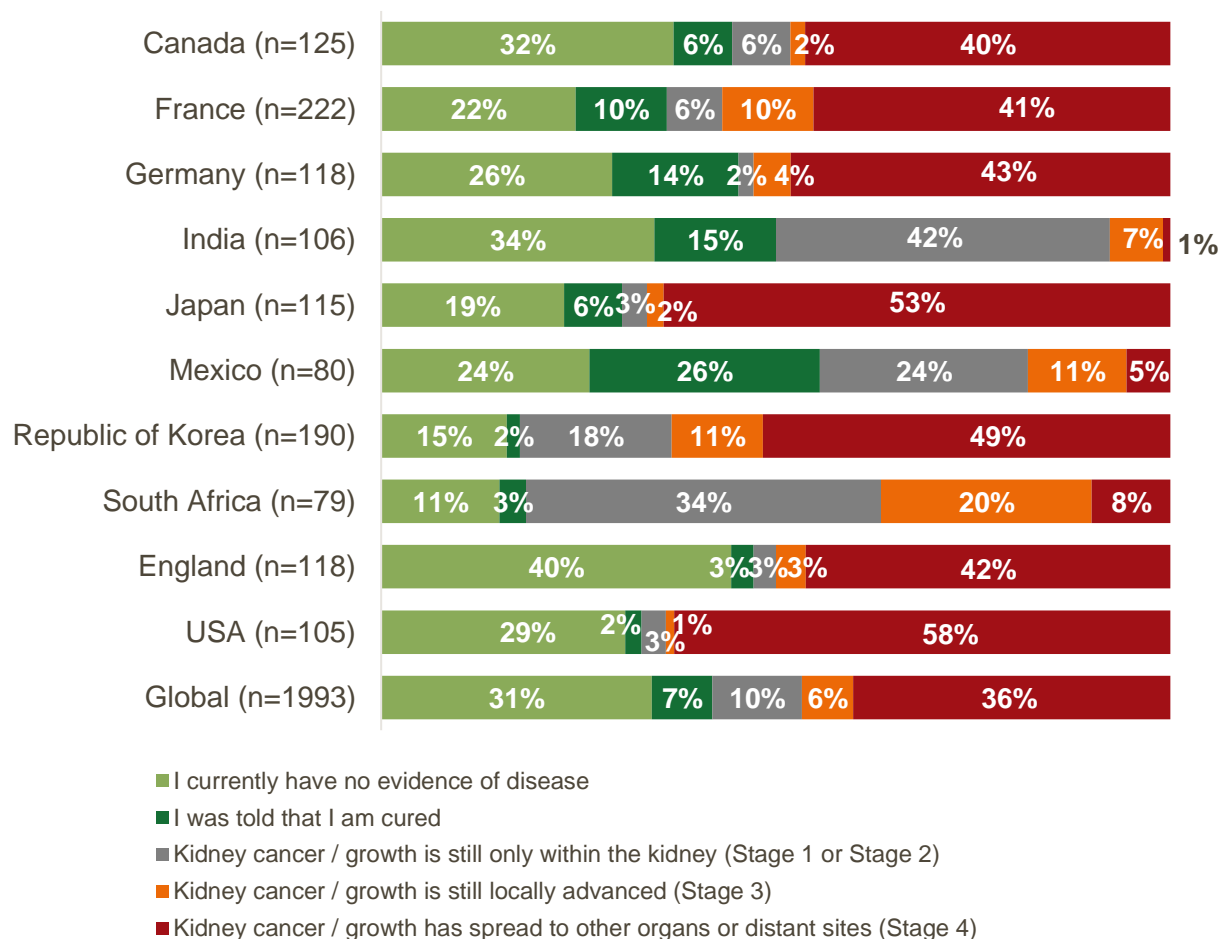
Current stage of kidney tumour(s)

With regard to current stage of kidney cancer and kidney growth, globally:

- 31% (n=610) have no current evidence of disease
- 7% (n=137) were told they are cured
- 10% (n=202) were in Stage 1 or Stage 2
- 6% (n=115) were in Stage 3
- 36% (n=716) were in Stage 4

See Figure 18 for full breakdown of current stage of kidney cancer and kidney growth by country.

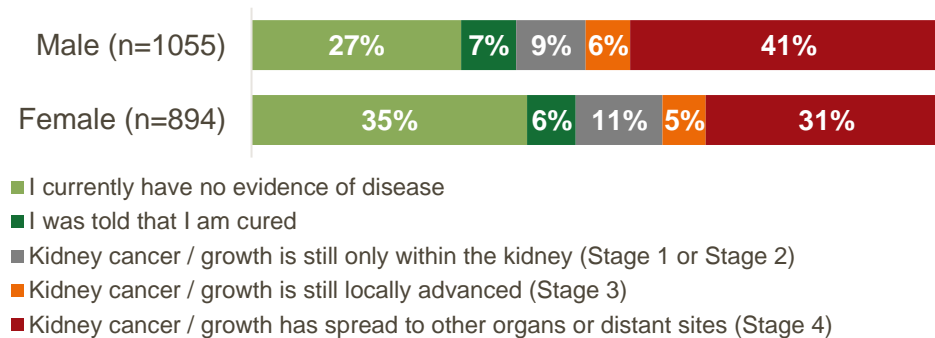
Figure 18. Q16 - Which of the following best describes your stage of kidney cancer or kidney growth TODAY? by country of residence



Please note the 'don't know' and 'other' responses have been excluded from this graph and percentages do not sum to 100%.

Differences by gender revealed that males (41%, n=437) were more likely to currently be in Stage 4 of their kidney cancer or kidney growth compared with female respondents (31%, n=273) (Figure 19).

Figure 19. Q16 - Which of the following best describes your stage of kidney cancer or kidney growth TODAY? by gender



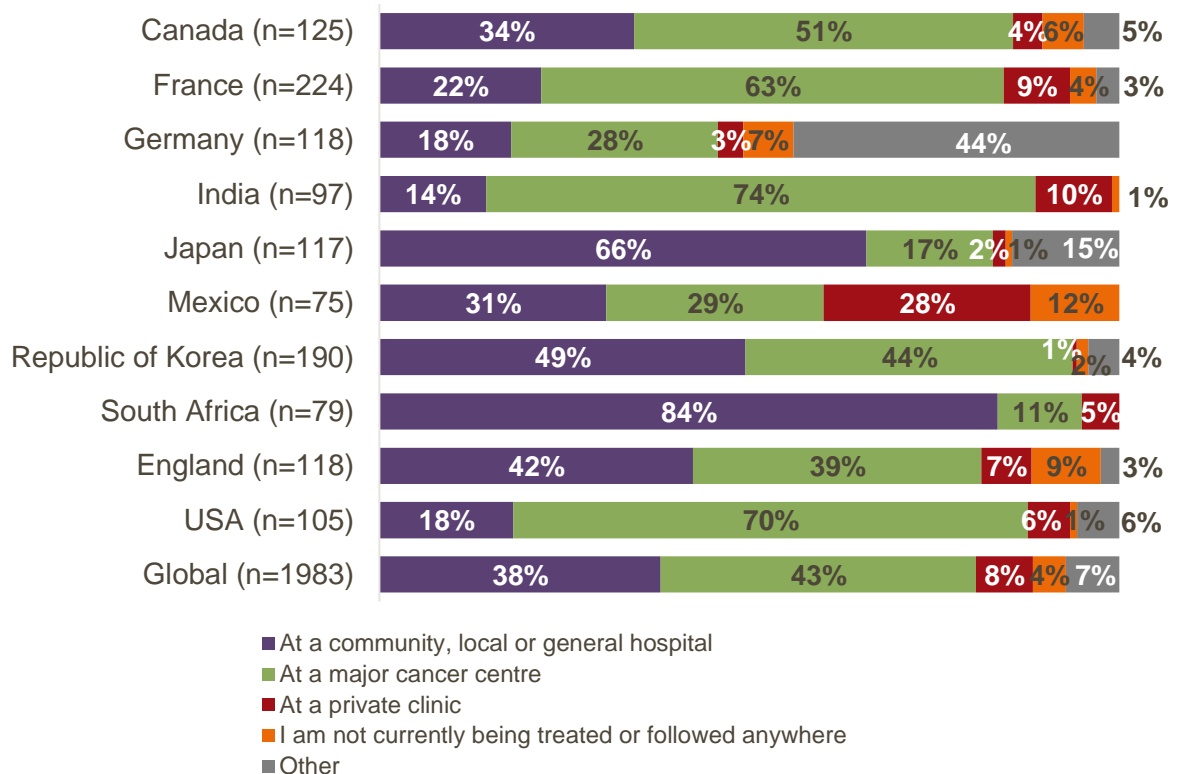
Please note the 'don't know' and 'other' responses have been excluded from this graph and percentages do not sum to 100%.

Place of current treatment centres and facilities varied by country of residence. For example, 66% (n=77) of Japan respondents were being treated or followed by a community, local or general hospital compared with only 14% (n=14) of India respondents.

In Germany, 44% (n=52) of respondents selected 'other'. Further inquiry found Kidney Cancer within Germany is often treated by specialist oncology departments which was not listed as a response option on the survey.

See Figure 20 for full details.

Figure 20. Q17 - Where are you CURRENTLY being treated or followed? by country of residence



Understanding of medical care and treatment

Respondents had varying levels of understanding regarding medical care and treatment. Globally, the following proportion of respondents reported they fully understood:

- Surgical options (72%, n=1353) (Figure 21)
- Immunotherapy options (53%, n=907) (Figure 22)
- Targeted therapy options (pills or tablets) (52%, n=891) (Figure 23)
- Active surveillance (52%, n=901) (Figure 26)
- Radiation therapy options (46%, n=759) (Figure 24)
- Ablative therapy options (cryoablation or radiofrequency ablation) (32%, n=528) (Figure 25)
- Adjuvant therapy (treatment aimed at reducing the chance of recurrence after surgery) (29%, n=459) (Figure 27)

When exploring differences by country of residence, full understanding of Adjuvant therapy was most common in France (44%, n=87) and the USA (42%, n=35), despite being least known globally (29%, n=459) – see Figure 27. Mexico had the lowest variance in the proportion of respondents understanding all aspects of care across Figures 21-27, ranging from 35% (n=27) of respondents understanding targeted therapy options (pills or tablets) to

55% (n=43) understanding surgical options. Canada had the highest variance in the proportion of respondents understanding all aspects of care across Figures 21-27, ranging from 77% (n=92) of respondents understanding surgical options to 23% (n=22) understanding Adjuvant therapy. Japan residents were least aware of Ablative therapy options (6%, n=6), Active surveillance (10%, n=10) and Adjuvant therapy (8%, n=8) relative to respondents from other countries.

Figure 21. Q18_1+ - Do you understand the following? - Surgical options by country of residence

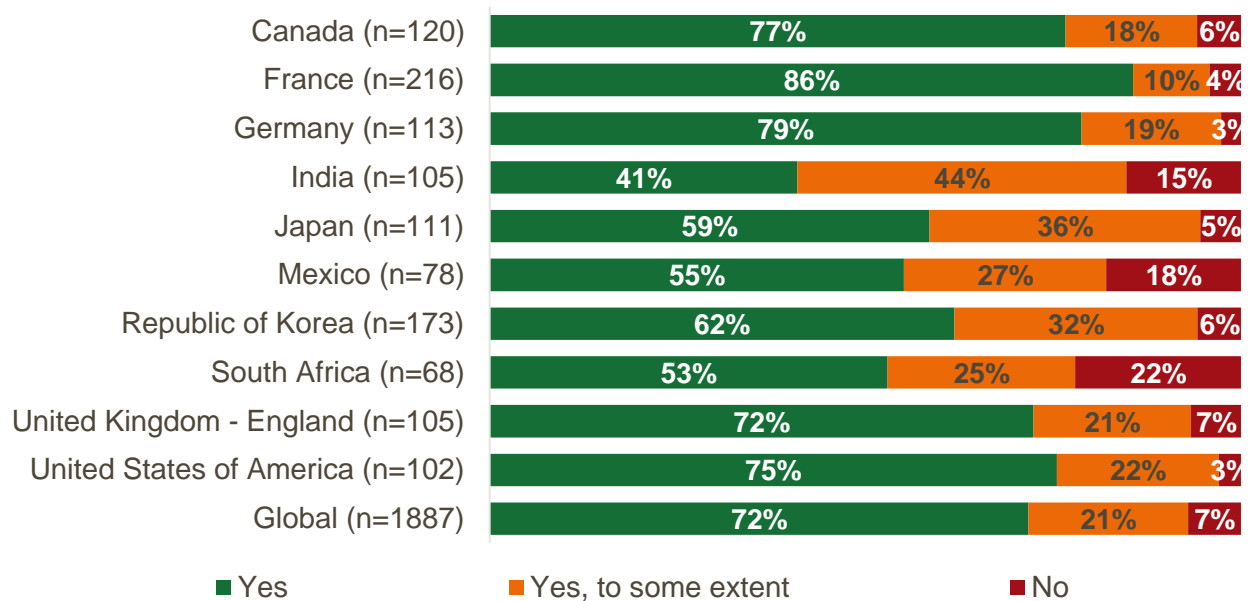


Figure 22. Q18_2+ - Do you understand the following? - Immunotherapy options by country of residence

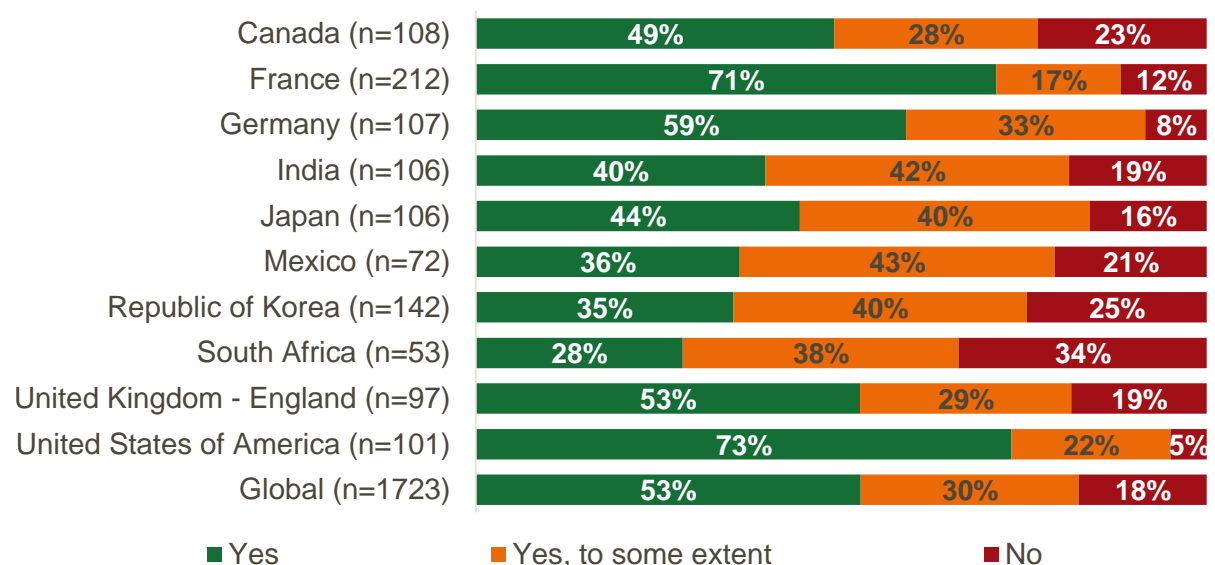


Figure 23. Q18_3+ - Do you understand the following? - Targeted therapy options (pills or tablets) by country of residence

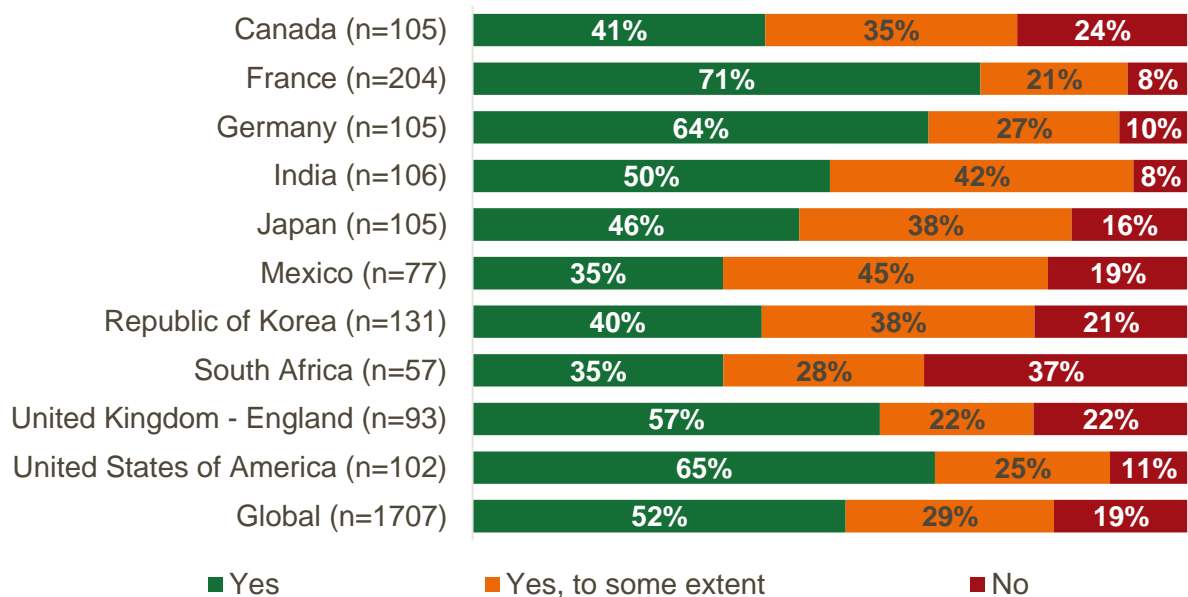


Figure 24. Q18_4+ - Do you understand the following? - Radiation therapy options by country of residence

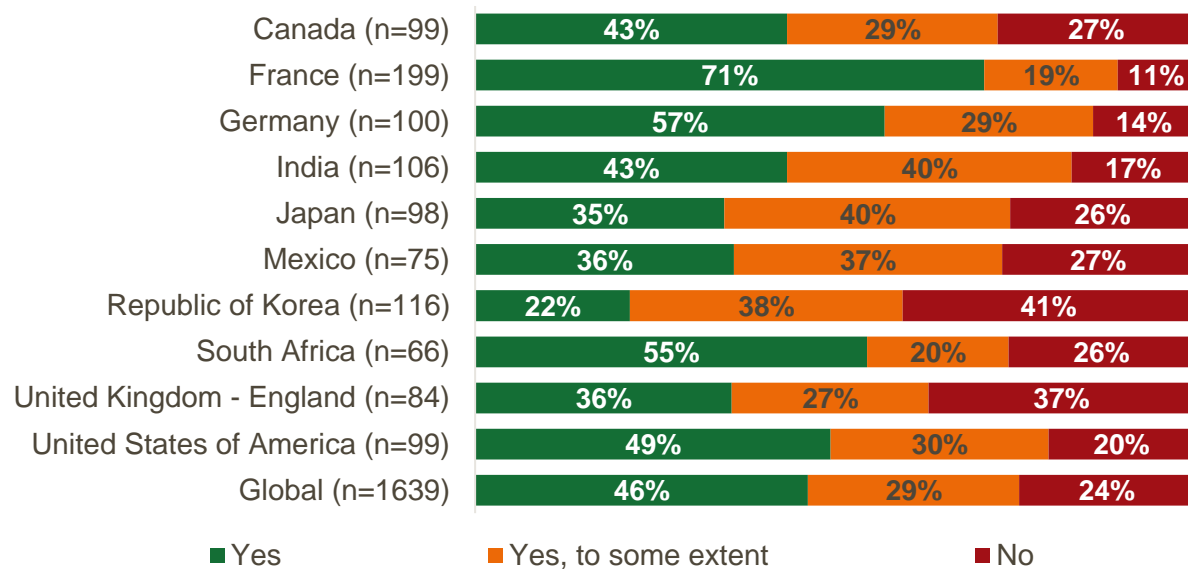


Figure 25. Q18_5+ - Do you understand the following? - Ablative therapy options (cryoablation or radiofrequency ablation) by country of residence

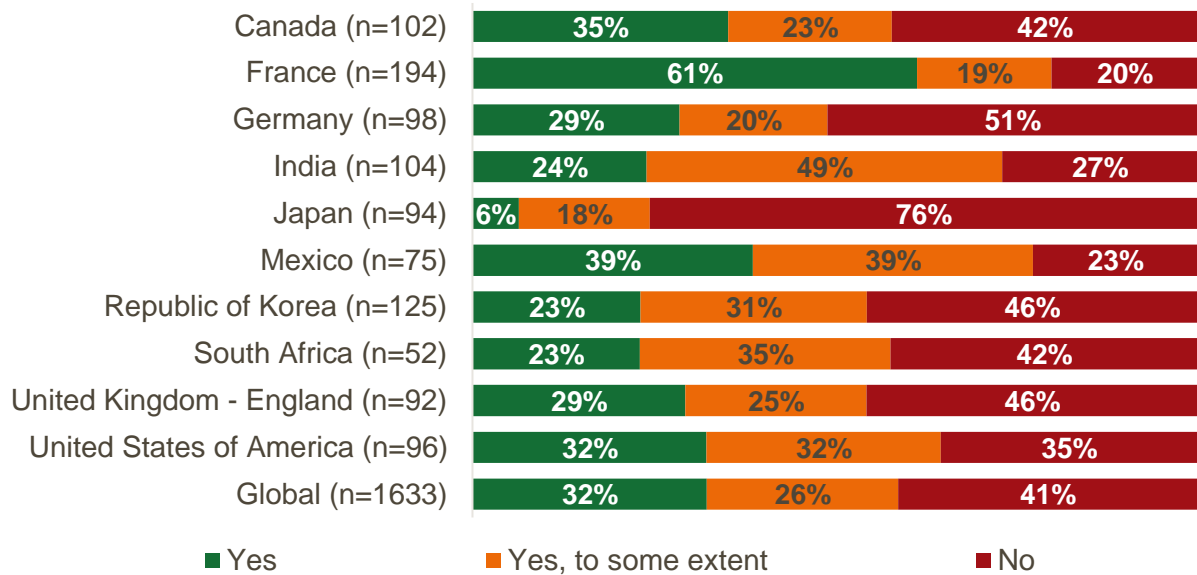


Figure 26. Q18_6+ - Do you understand the following? - Active surveillance by country of residence

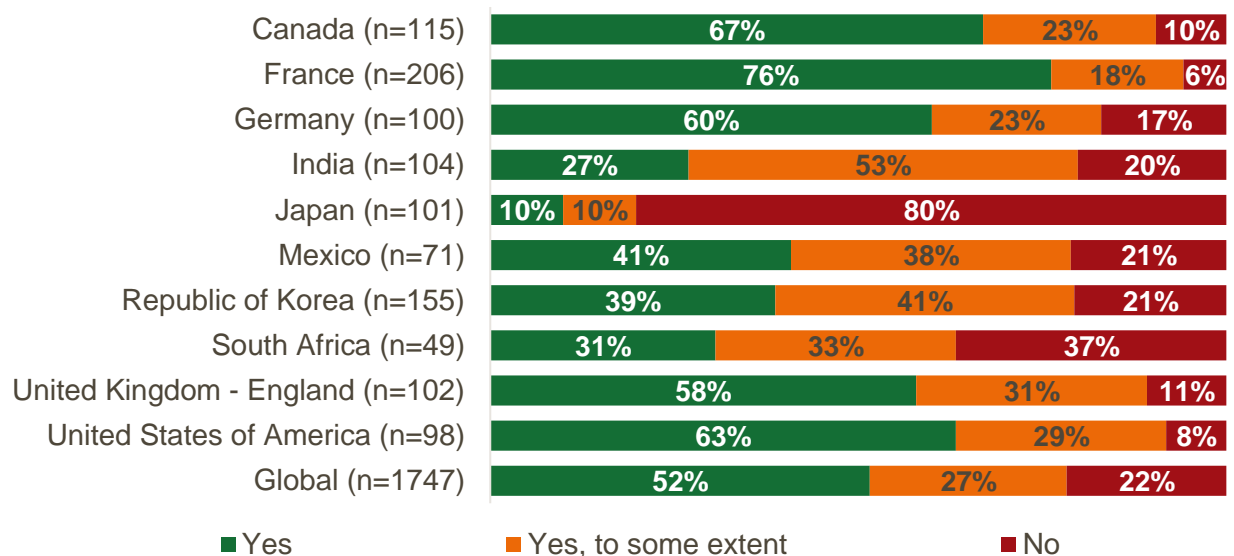


Figure 27. Q18_7+ - Do you understand the following? - Adjuvant therapy (treatment aimed at reducing the chance of recurrence after surgery) by country of residence

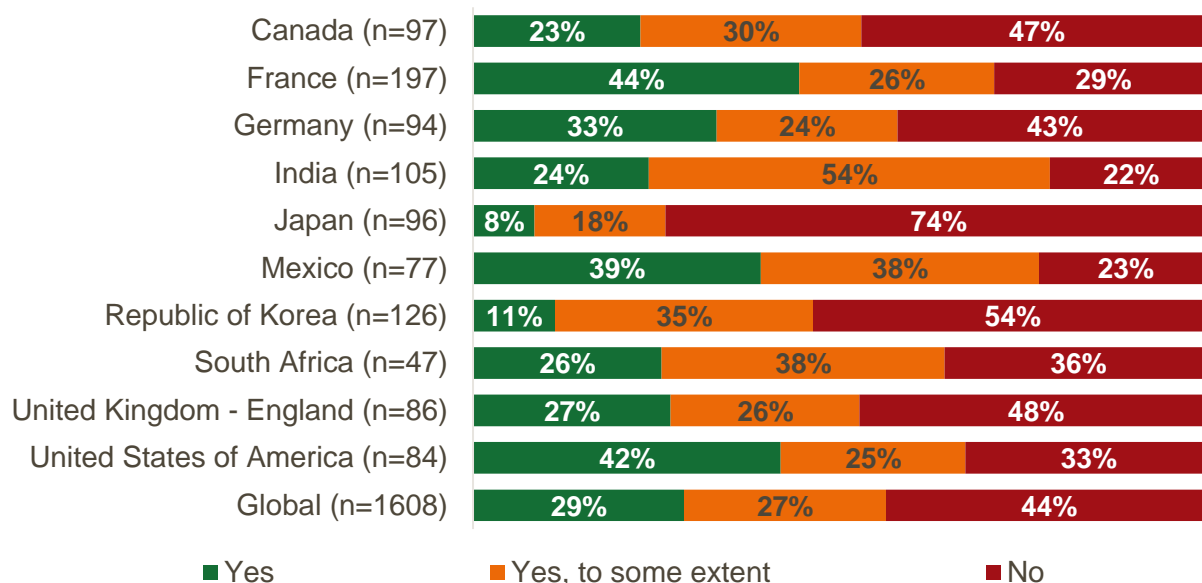


Table 7 details the proportion of respondents who fully understood the varying aspects of medical care and treatment by current stage of cancer. Respondents currently at a localised stage of cancer were less likely than those at an advanced stage or those with no current evidence of cancer to fully understand all aspects of care and treatment, with the exception of Ablative therapy options (cryoablation or radiofrequency ablation). This is perhaps an expected finding, given respondents at an advanced stage or those that have no current evidence of cancer may be further along in their health journey than those remaining at a localised stage.

Table 7. Q18+ - Do you understand the following? – those responding ‘yes’ by current stage of cancer

	Current stage of cancer		
	Localised	Advanced	No evidence
Maximum base across all aspects for Q18 (n=)	193	779	712
Surgical options	53%	69%	78%
Immunotherapy options	26%	64%	46%
Targeted therapy options (pills or tablets)	28%	66%	42%
Radiation therapy options	36%	53%	42%
Ablative therapy options (cryoablation or radiofrequency ablation)	37%	33%	30%
Active surveillance	39%	54%	53%
Adjuvant therapy (treatment aimed at reducing the chance of recurrence after surgery)	24%	29%	29%

Understanding of supportive care

Respondents had varying levels of understanding regarding supportive care. Globally, the following proportion of respondents reported they fully understood:

- The importance of lifestyle choices for their wellbeing (e.g., avoiding smoking, being active) (71%, n=1374) (Figure 30)
- The importance of good nutrition for their well-being (58%, n=1116) (Figure 29)
- Palliative/ supportive care (51%, n=910) (Figure 28)
- Their local guidelines for kidney cancer care and follow up (43%, n=807) (Figure 32)
- Complementary therapies (e.g., meditation, etc.) (38%, n=687) (Figure 31)

Japan responses had the most variance in the extent of understanding across all aspects of supportive care (Figures 28-32), ranging from 58% (n=67) of respondents understanding the importance of lifestyle choices for wellbeing (e.g., avoiding smoking, being active) to 7% (n=8) understanding complementary therapies (e.g. meditation, etc.).

Figure 28. Q19_1+ - Do you understand the following - Palliative/ supportive care by country of residence

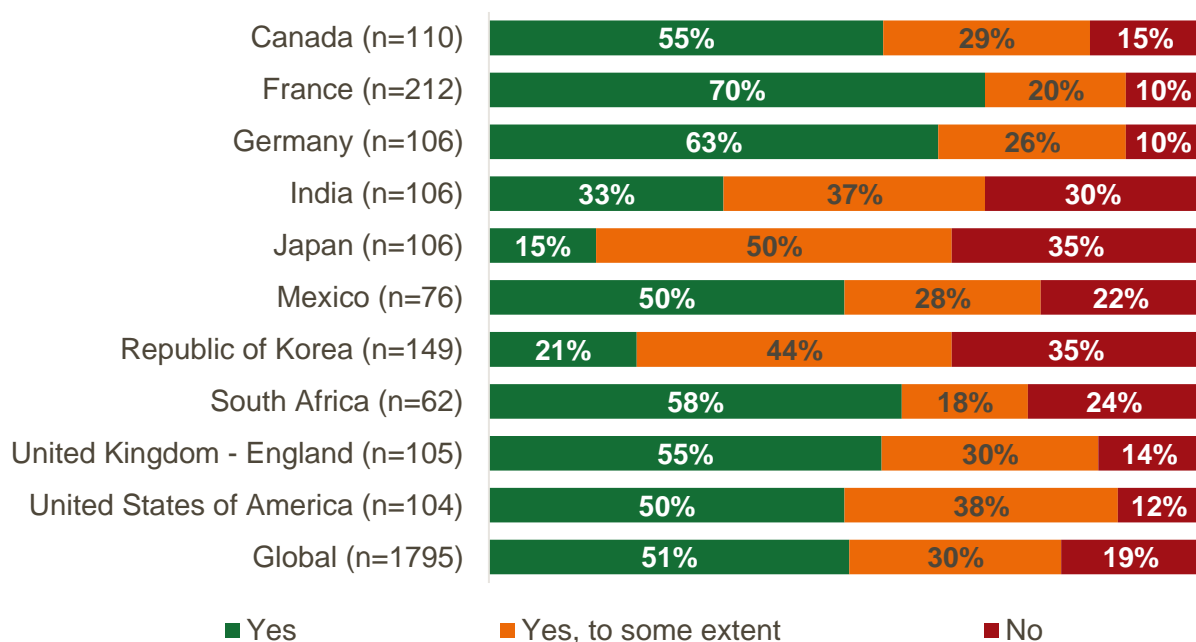


Figure 29. Q19_2+ - Do you understand the following - The importance of good nutrition for my well-being by country of residence

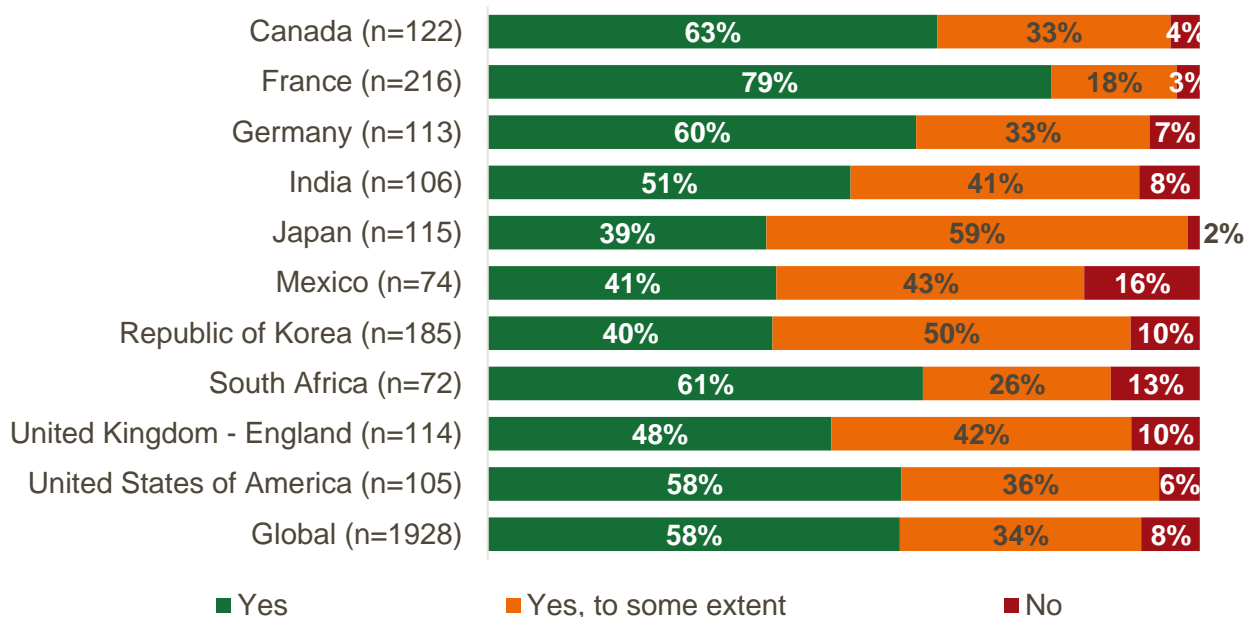


Figure 30. Q19_3+ - Do you understand the following - The importance of lifestyle choices for my wellbeing (e.g. avoiding smoking, being active) by country of residence

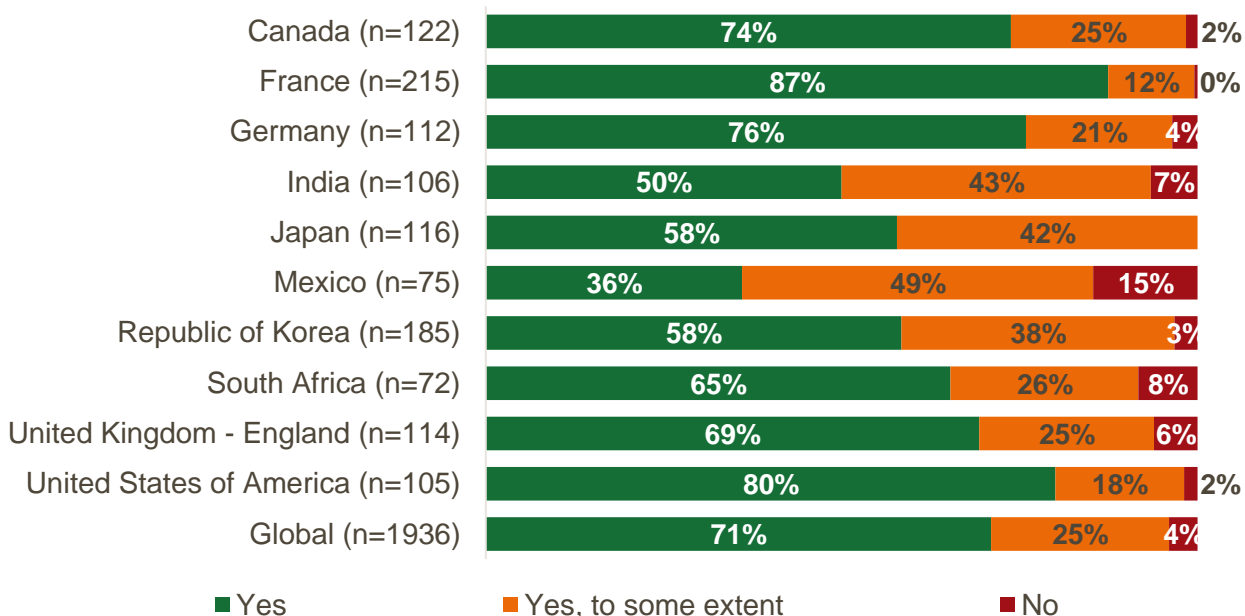


Figure 31. Q19_4+ - Do you understand the following - Complementary therapies (e.g. meditation, etc.) by country of residence

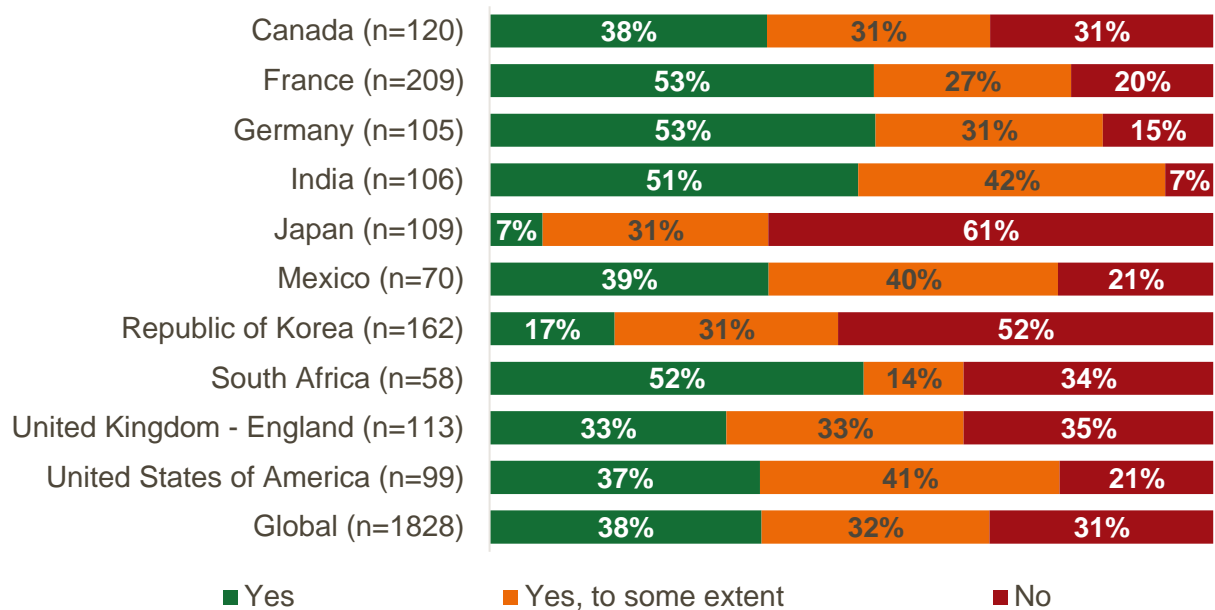


Figure 32. Q19_5+ - Do you understand the following - My local guidelines for kidney cancer care and follow up by country of residence

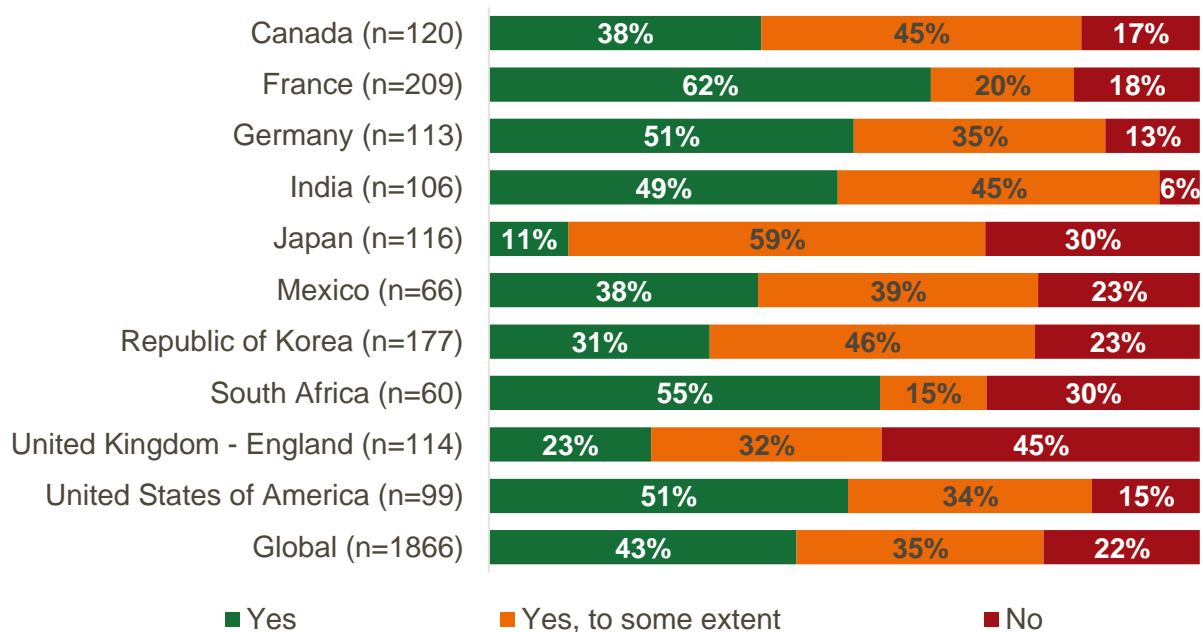


Table 8 details the proportion of respondents who fully understood the varying aspects of supportive care by current stage of cancer. Similar to findings for understanding of medical care and treatment, respondents currently at a localised stage of cancer were less likely than those at an advanced stage or with no evidence of cancer to fully understand all aspects, with the exception of complementary therapies such as meditation (34%, n=60) which was a similar level of understanding to those at an advanced stage (33%, n=255). Again, this is perhaps due to respondents at an advanced stage or with no current evidence of cancer being further along in their health journey than those remaining at a localised stage.

Table 8. Q19+ - Do you understand the following? – those responding ‘yes’ by current stage of cancer

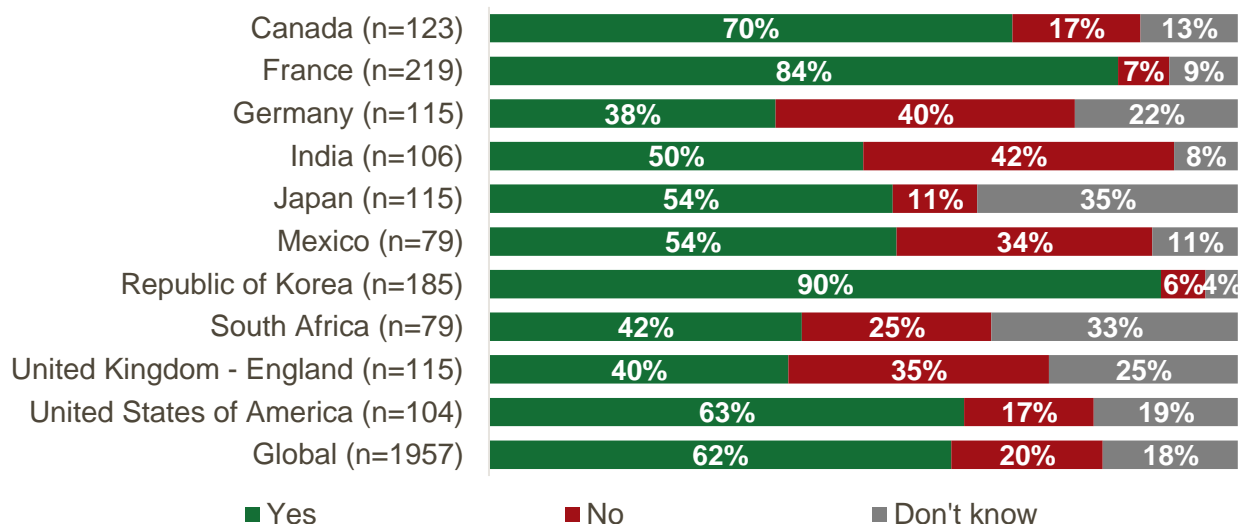
	Current stage of cancer		
	Localised	Advanced	No evidence
Maximum base across all aspects for Q19 (n=)	98	587	541
Palliative/ supportive care	29%	50%	57%
The importance of good nutrition for my well-being	42%	58%	62%
The importance of lifestyle choices for my wellbeing (e.g. avoiding smoking, being active)	51%	72%	75%
Complementary therapies (e.g. meditation, etc.)	34%	33%	43%
My local guidelines for kidney cancer care and follow up	33%	42%	47%

Biopsy and active surveillance for small renal mass

Willingness to participate in active surveillance

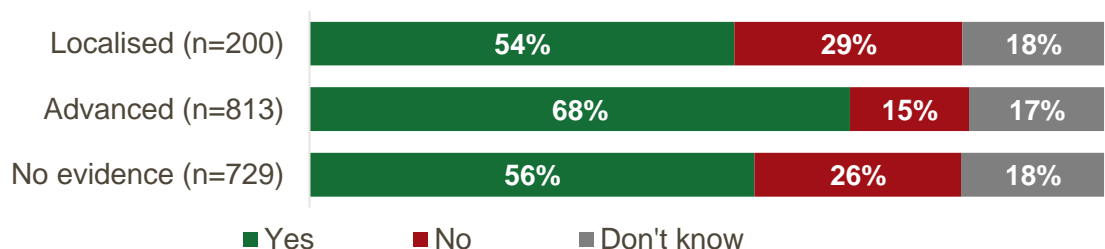
Globally, almost two thirds of respondents (62%, n=1208) if diagnosed with a small renal mass, would be willing to participate in Active Surveillance with regular imaging such as ultrasound and CT if it were recommended by their doctor (Figure 33). The majority of respondents in the Republic of Korea (90%, n=166) would be willing to participate, compared with just over one third of respondents in Germany (38%, n=44).

Figure 33. 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? by country of residence



Respondents currently at an advanced stage of cancer were more likely to be willing to participate in this form of Active Surveillance (68%, n=556) than those at localised stage (54%, n=108) or those with no current evidence of cancer (56%, n=410) (Figure 34).

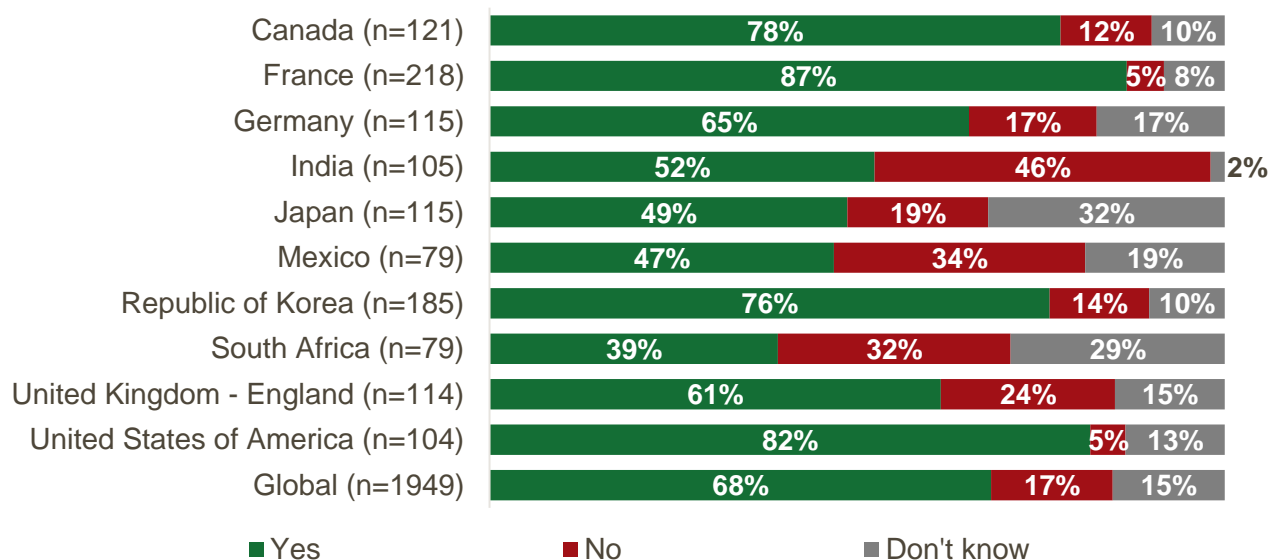
Figure 34. Q20 - When a small renal growth (less than 4 cm) is detected on a scan, it can often be managed without invasive treatment such as surgery. If your doctor recommended Active Surveillance with regular imaging such as ultrasound and CT, would you be willing to participate? By current stage of cancer



Biopsy of a small renal mass

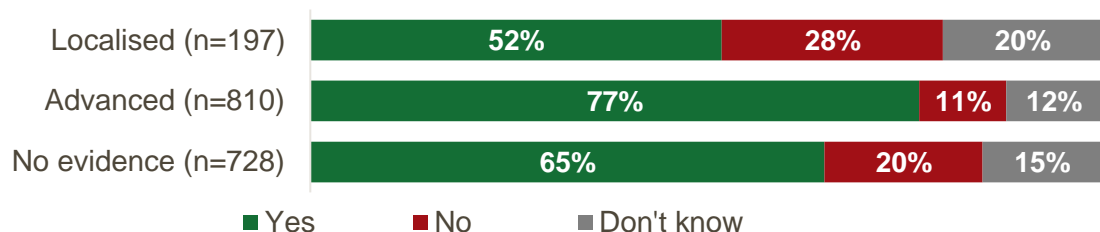
Globally, more than two thirds of respondents (68%, n=1330) would be willing to have a biopsy of a small renal growth to help form a more precise diagnosis and treatment plan (Figure 35). Respondents residing in the USA were most willing to have this type of biopsy (82%, n=85), respondents from South Africa were least willing (39%, n=31).

Figure 35. 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? by country of residence



Three in four respondents (77%, n=624) currently at an advanced stage of cancer would be willing to have a biopsy of a small renal growth to help form a more precise diagnosis and treatment plan. This is compared with 52% (n=102) currently at a localised stage and 65% (n=473) of respondents with no current evidence of cancer (Figure 36).

Figure 36. 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? By current stage of cancer



Length of surveillance scanning following surgery

Figures highlighted in green in Table 9 indicate the most preferred length of surveillance globally and for each country. One third of respondents (32%, n=638) globally would prefer to have regular imaging scans for surveillance following surgery for kidney cancer or kidney growth for less than 2 years. 13% (n=257) would prefer to have this type of surveillance for between 2 and 6 years, while 23% (n=455) preferred more than 6 years. 28% (n=543) of respondents said they would make this decision based on their healthcare team's opinion.

There is significant variation by country of residence. Respondents in Germany (50%, n=58) and England (44%, n=51) were most likely to prefer to have regular imaging scans or surveillance for more than 6 years. Respondents in Japan (41%, n=47) and the USA (30%, n=31) were most likely to report they would make this decision based on their healthcare team's opinion. In contrast, just 2% (n=2) of respondents in India and 0% (n=0) of respondents in Mexico reported they would make this decision based on their healthcare team's opinion. Local access to follow up imaging is likely to contribute to these differences, and additional research is needed to fully understand this data.

Table 9. 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? by country of residence

	Global	Canada	France	Germany	India	Japan	Mexico	Rep. of Korea	South Africa	U.K. England	USA
Base (n=)	1965	121	220	116	106	115	79	186	79	115	105
Less than 2 years	32%	41%	55%	9%	58%	5%	34%	46%	56%	28%	25%
2 to 4 years	6%	2%	2%	3%	32%	2%	28%	4%	5%	1%	4%
4 to 6 years	7%	10%	0%	8%	1%	3%	19%	7%	1%	5%	10%
More than 6 years	23%	19%	4%	50%	0%	40%	8%	6%	1%	44%	26%
Don't know	4%	2%	2%	1%	8%	9%	11%	0%	0%	5%	7%
I would decide based on my healthcare team's opinion	28%	25%	37%	29%	2%	41%	0%	37%	37%	17%	30%

Figures highlighted in green in

Table 10 indicate the most preferred length of surveillance by current stage of cancer. Respondents at a localised stage were most likely to prefer surveillance to last less than 2 years (50%, n=99), while respondents with no current evidence of cancer were most likely to prefer surveillance to last more than 6 years (31%, n=230). Respondents currently at an advanced stage were most likely to report they would make this decision based on the opinion of their healthcare team (35%, n=286).

Table 10. 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? by current stage of cancer

Base (n=)	Current stage of cancer		
	Localised 200	Advanced 815	No evidence 733
Less than 2 years	50%	33%	28%
2 to 4 years	13%	3%	9%
4 to 6 years	6%	5%	9%
More than 6 years	6%	20%	31%
Don't know	6%	4%	2%
I would decide based on my healthcare team's opinion	20%	35%	20%

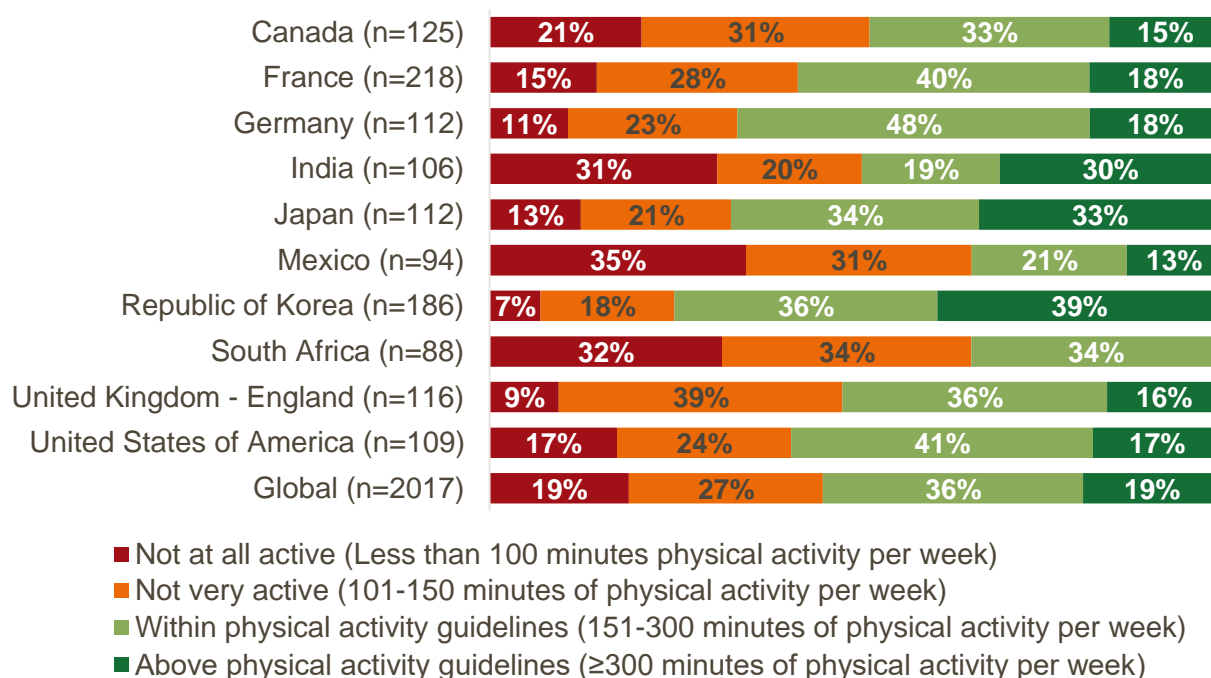
Quality of life

Current level of physical activity

Globally, 54% (n=1097) of respondents reported their current level of physical activity as being within or above physical activity guidelines (equal to or more than 151 minutes per week), while 46% (n=920) reported that their current level of physical activity did not meet physical activity guidelines. As indicated in Figure 37, current level of physical activity varies greatly by country of residence. The following countries reported a higher level of physical activity within or above guidelines than the global result:

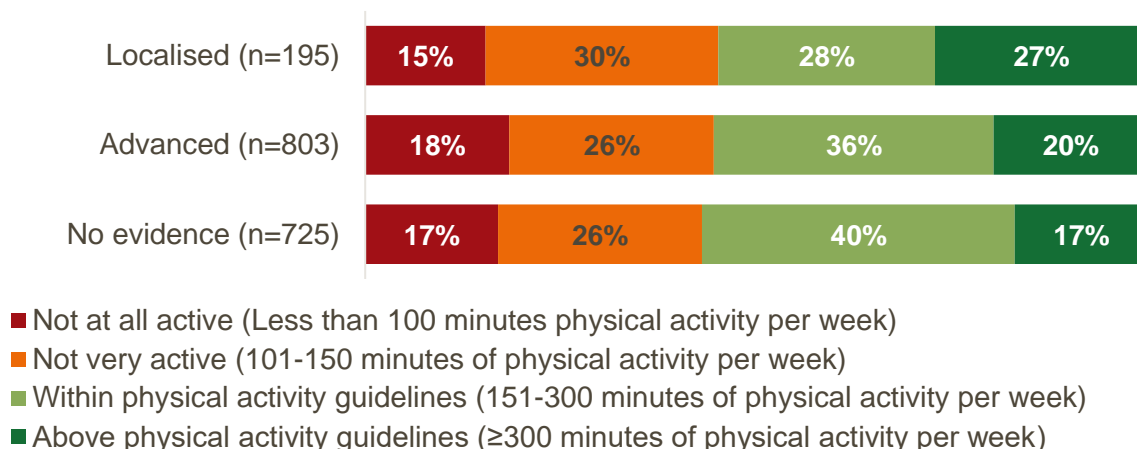
- Republic of Korea (75%, n=139)
- Japan (67%, n=75)
- Germany (66%, n=74)
- USA (59%, n=64)
- France (58%, n=126)

Figure 37. Q23+ - I would describe my current level of physical activity (defined as physical activity that lasts at least 10 minutes) as: by country of residence



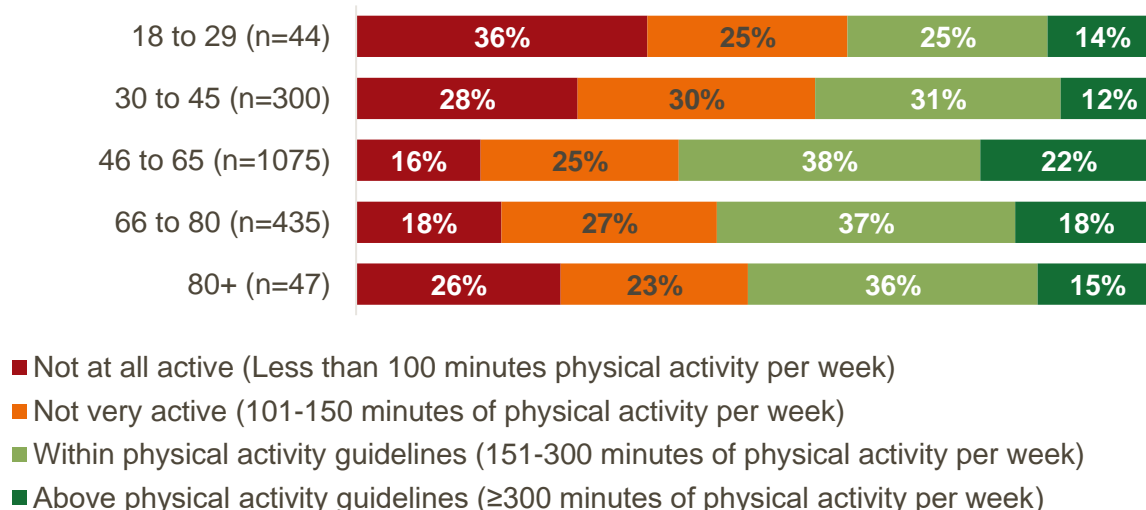
Respondents currently at a localised stage (27%, n=53) of cancer were more likely to report their current level of physical activity as being above physical activity guidelines (≥300 minutes of physical activity per week) than those at an advanced stage (20%, n=158) or with no evidence (17%, n=123). See Figure 38 for full details.

Figure 38. Q23+ - I would describe my current level of physical activity (defined as physical activity that lasts at least 10 minutes) as: by current stage of cancer



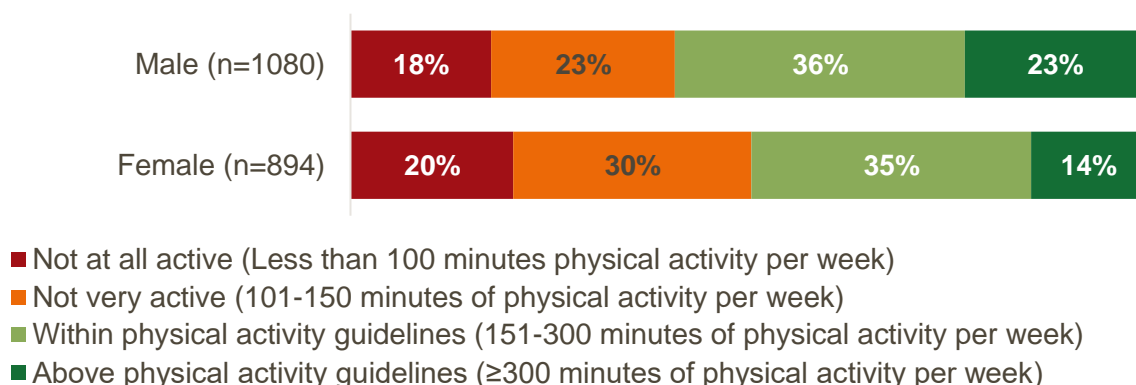
Older respondents aged 46 to 65 (60%, n=642), 66 to 80 (55%, n=239) and over 80 (51%, n=24) were more likely to report they were physically active (equal to or more than 151 minutes per week) than younger respondents aged 18 to 29 (39%, n=17) and 30 to 45 (43%, n=128) (Figure 39).

Figure 39. Q23+ - I would describe my current level of physical activity (defined as physical activity that lasts at least 10 minutes) as: by age group



Males (59%, n=639) were more likely to report they were physically active (equal to or more than 151 minutes per week) than females (50%, n=443) (Figure 40).

Figure 40. Q23+ - I would describe my current level of physical activity (defined as physical activity that lasts at least 10 minutes) as: by gender



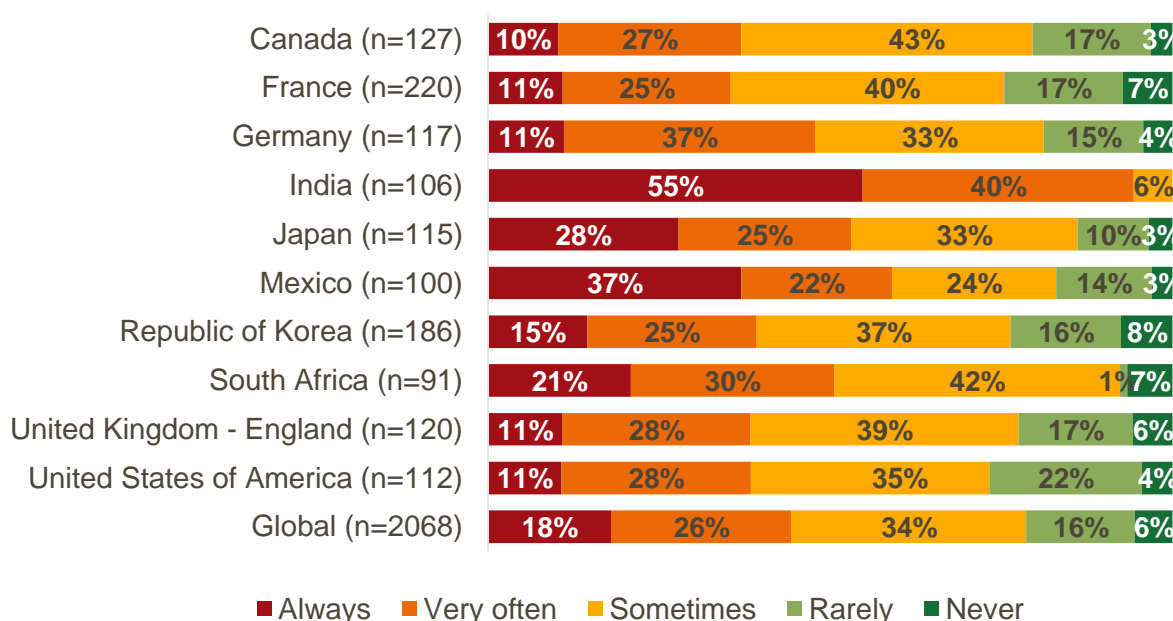
Emotional wellbeing

A diagnosis of kidney cancer or a kidney growth can negatively impact more than a person's physical health. Recognising the impact to emotional and psychological wellbeing is vital to providing the support patients and their caregivers need. The IKCC survey 2022 enquired about the extent to which the following emotional aspects have impacted patient's sense of emotional wellbeing since their diagnosis.

General anxiety

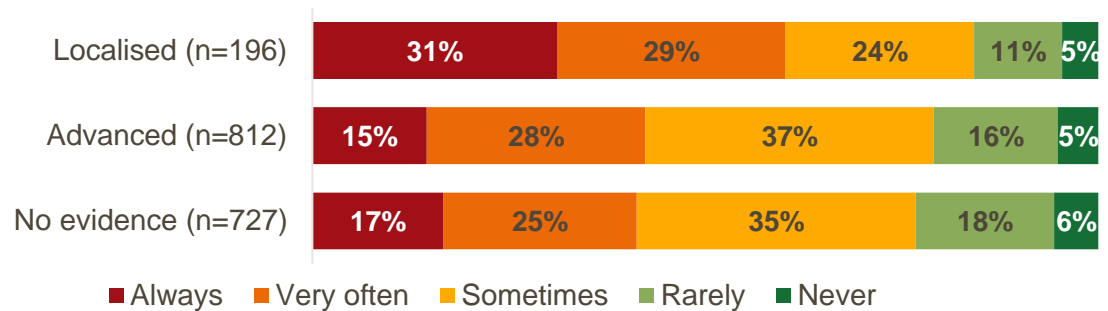
Almost one fifth of respondents globally reported that general anxiety always impacts their sense of emotional wellbeing since their diagnosis (18%, n=372). Residents in India were most impacted, with 94% (n=100) reporting they always or very often experience general anxiety (Figure 41).

Figure 41. Q24_1 - How often have the following impacted your sense of emotional well-being since your diagnosis? - General anxiety by country of residence



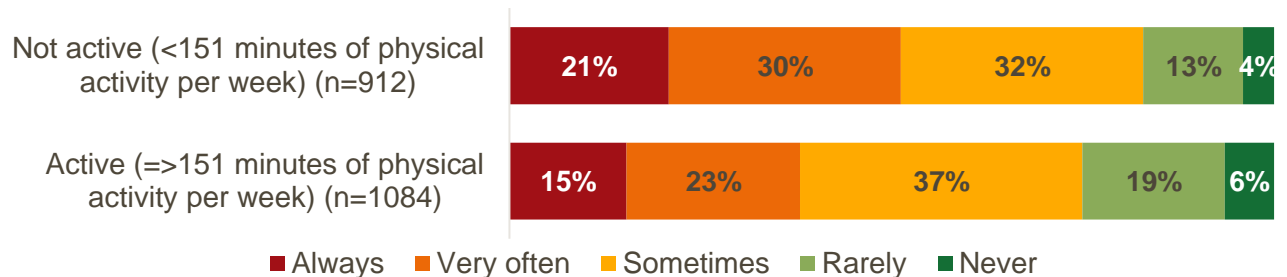
Respondents currently at a localised stage of disease were twice as likely to always experience general anxiety since their diagnosis (31%, n=61) than respondents at an advanced stage (15%, n=118) (Figure 42).

Figure 42. Q24_1 - How often have the following impacted your sense of emotional well-being since your diagnosis? - General anxiety by current stage of cancer



Higher levels of general anxiety were reported in those who reported they are not active. 51% (n=467) of respondents who said they were not physically active reported always or very often feeling general anxiety, compared with 38% (n=412) of active respondents (Figure 43).

Figure 43. Q24_1 - How often have the following impacted your sense of emotional well-being since your diagnosis? - General anxiety by current level of physical activity



Disease-related anxiety

Response to disease-related anxiety was very similar to general anxiety results, with 20% (n=409) of respondents globally always experiencing disease-related anxiety since diagnosis. Respondents who were most likely to report always experiencing disease-related anxiety were:

- Indian residents (34%, n=36) (Figure 44)
- Respondents at a localised current stage of cancer (27%, n=52) (Figure 45)
- Those who were not physically active (23%, n=211) (Figure 46)

Figure 44. Q24_2 - How often have the following impacted your sense of emotional well-being since your diagnosis? - Disease-related anxiety by country of residence

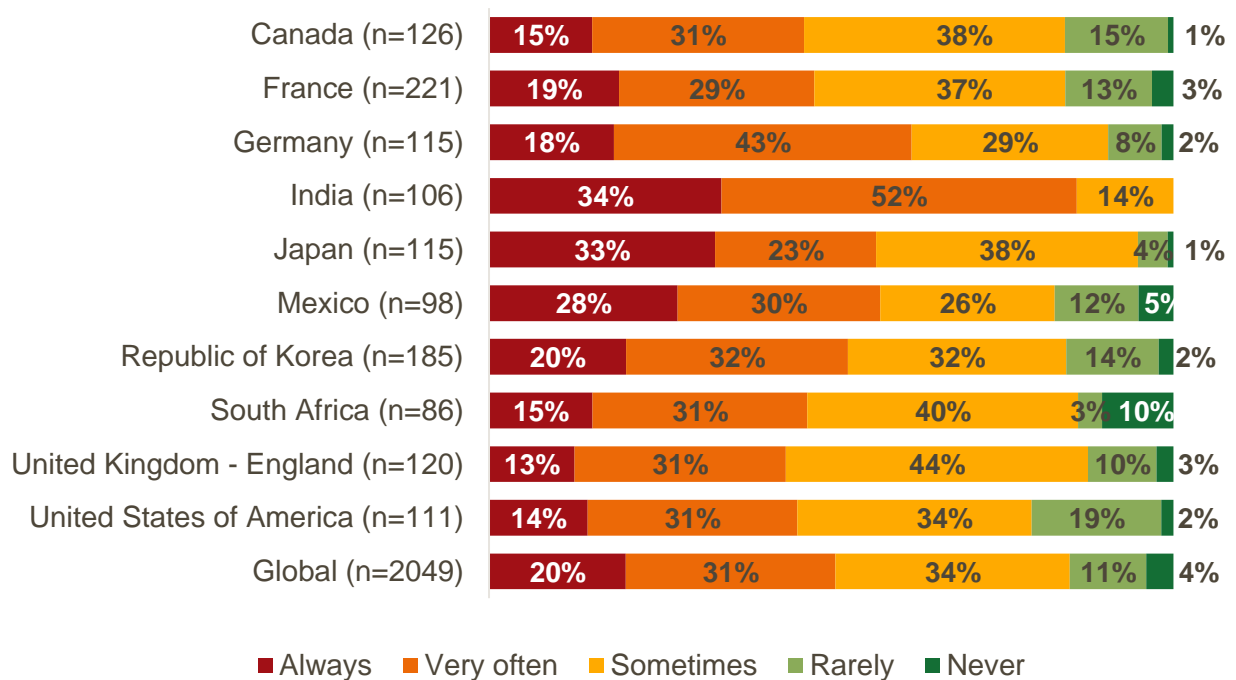


Figure 45. Q24_2 - How often have the following impacted your sense of emotional well-being since your diagnosis? - Disease-related anxiety by current stage of cancer

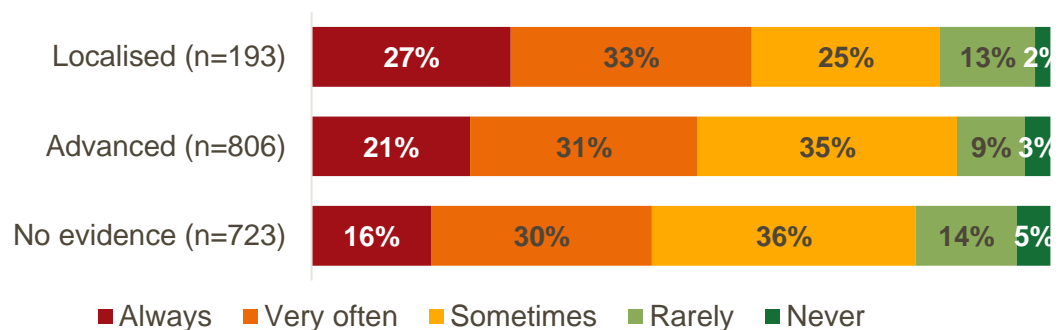
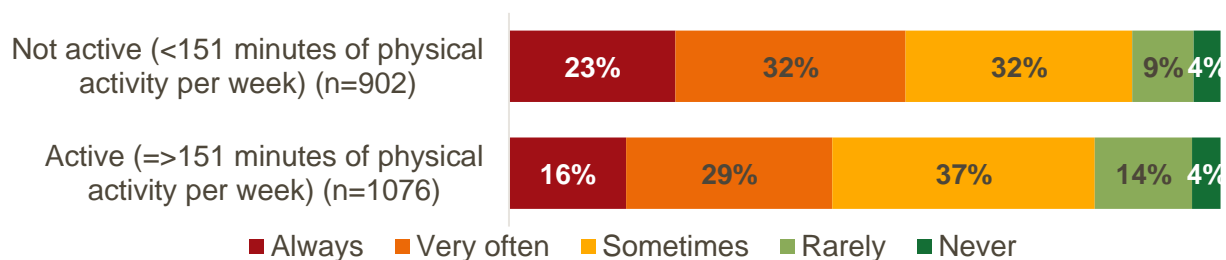


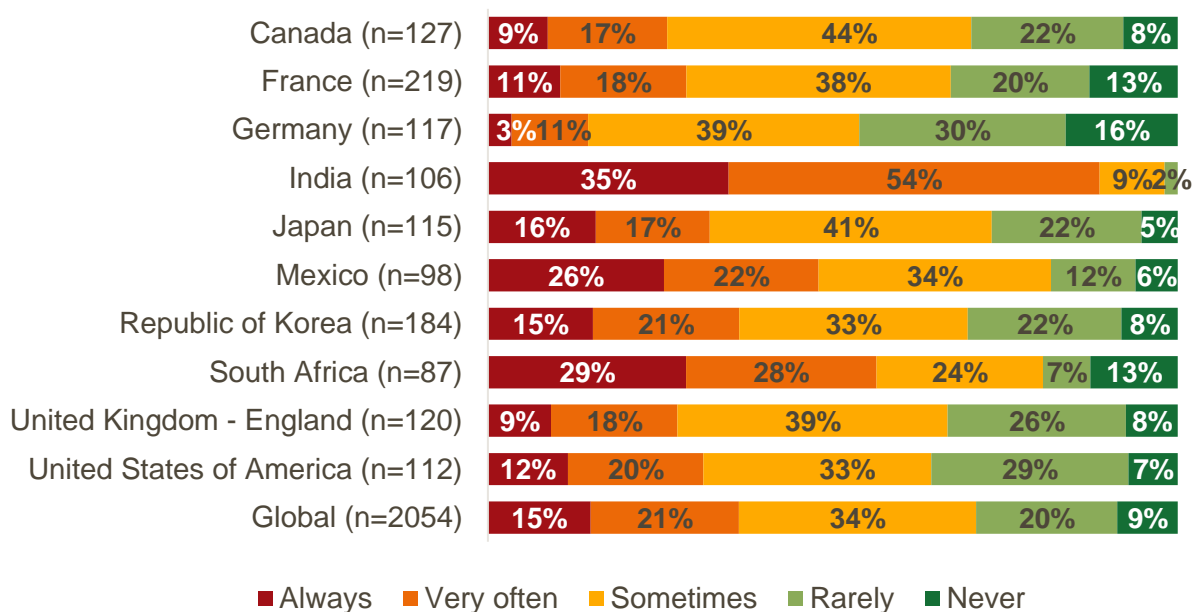
Figure 46. Q24_2 - How often have the following impacted your sense of emotional well-being since your diagnosis? - Disease-related anxiety by current level of physical activity



Fear of dying

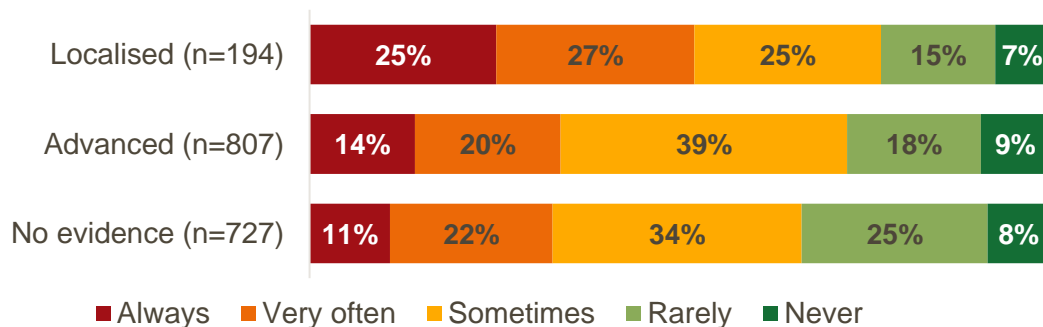
Globally, more than one third of respondents (36%, n=747) reported they always or very often experience fear of dying. 34% (n=707) reported they experience this fear sometimes, and 29% (n=600) said they rarely or never experience fear of dying. The majority of respondents in India (89%, n=94) said they always or very often experience fear of dying. This was substantially higher than in other countries and in stark contrast with Germany, where just 15% (n=17) always or very often experience fear of dying (Figure 47; data from an open-ended question (Q34); free text responses are not reported structurally in this report).

Figure 47. Q24_3 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Fear of dying by country of residence



Respondents currently at a localised stage of disease were more than twice as likely to always experience fear of dying since their diagnosis (25%, n=49) than respondents with no current evidence of disease (11%, n=79) (Figure 48Error! Not a valid bookmark self-reference.).

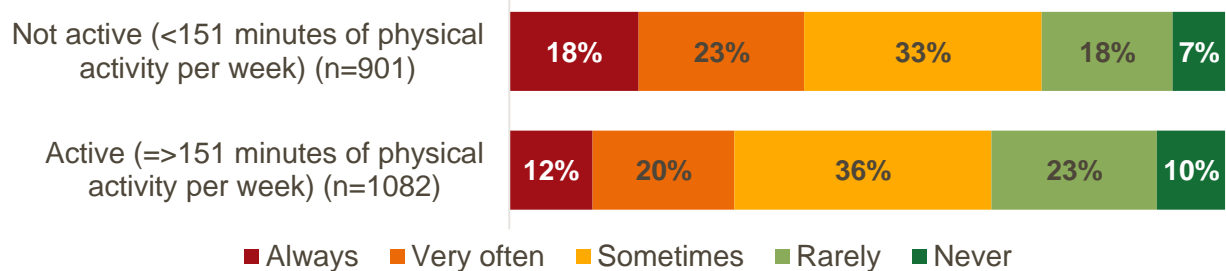
Figure 48. Q24_3 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Fear of dying by current stage of cancer





Respondents who were not physically active were more likely to always or very often report experiencing fear of dying (41%, n=371), than physically active respondents (31%, n=340) (Figure 49).

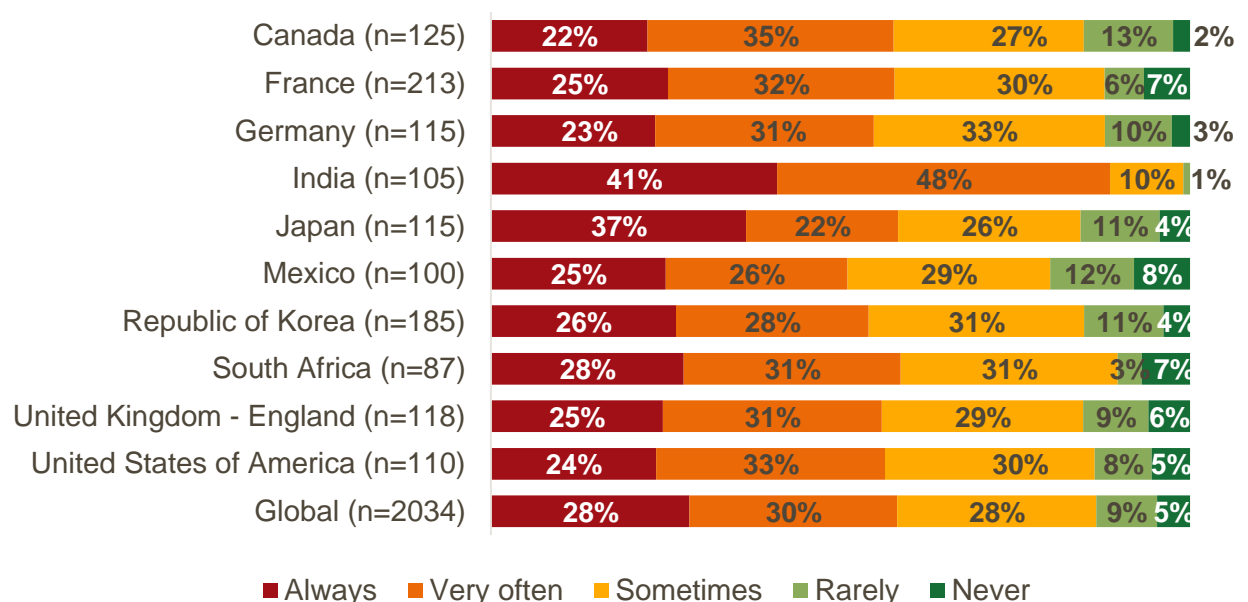
Figure 49. Q24_3 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Fear of dying by current level of physical activity



Fear of the cancer/growth coming back (recurrence)

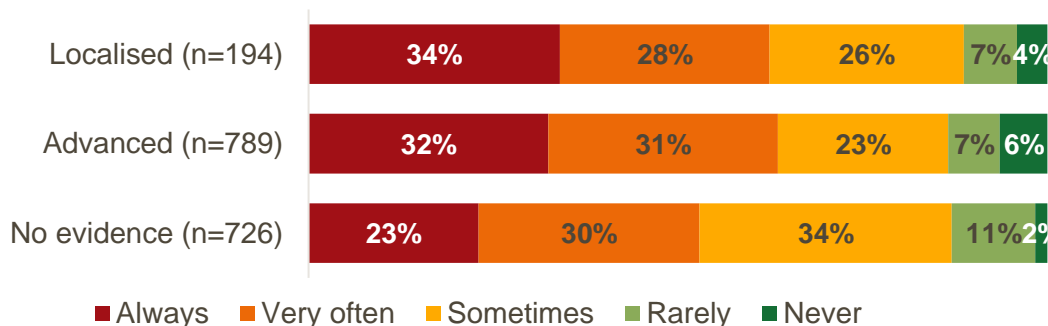
More than half of respondents globally (58%, n=1182) always or very often reported experiencing fear of recurrence. Impact to wellbeing was greatest in India, where almost all respondents (99%, n=104) experienced fear of recurrence always, very often or sometimes. 0% (n=0) of India residents said they never experience this form of fear (Figure 50).

Figure 50. 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) by country of residence



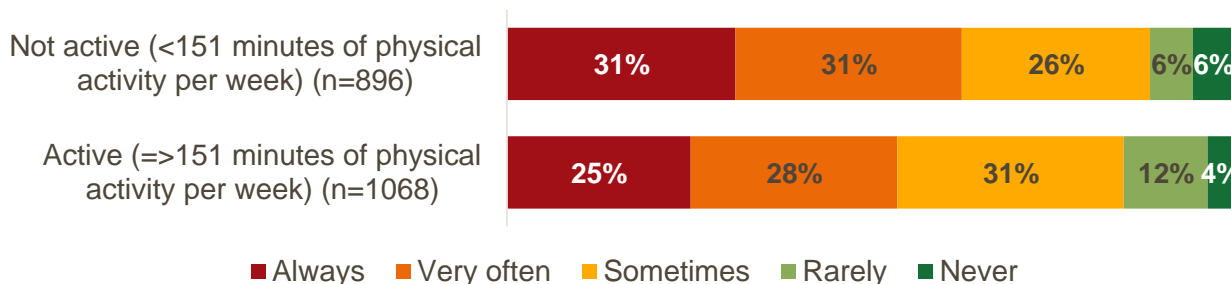
Respondents with no current evidence of cancer (23%, n=167) were less likely to report they always experienced fear of recurrence, than respondents at a localised (34%, n=66) or advanced (32%, n=256) stage of disease (Figure 51).

Figure 51. 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) by current stage of cancer



Almost two thirds (63%, n=561) of respondents who were not physically active, always or very often experience fear of recurrence. This is comparable to 54% (n=574) of active respondents (Figure 52Error! Not a valid bookmark self-reference.).

Figure 52. 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) by current level of physical activity



Sadness or depression

One in ten respondents globally reported they always experience sadness or depression since their diagnosis (11%, n=235). Respondents who were most likely to always be impacted by sadness and depression were:

- India residents (38%, n=40) (Figure 53)
- Respondents at a localised current stage of cancer (21%, n=41) (Figure 54Figure 45)
- Respondents who were not physically active (15%, n=136) (Figure 55Figure 46)

Figure 53. Q24_5 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Sadness or depression by country of residence

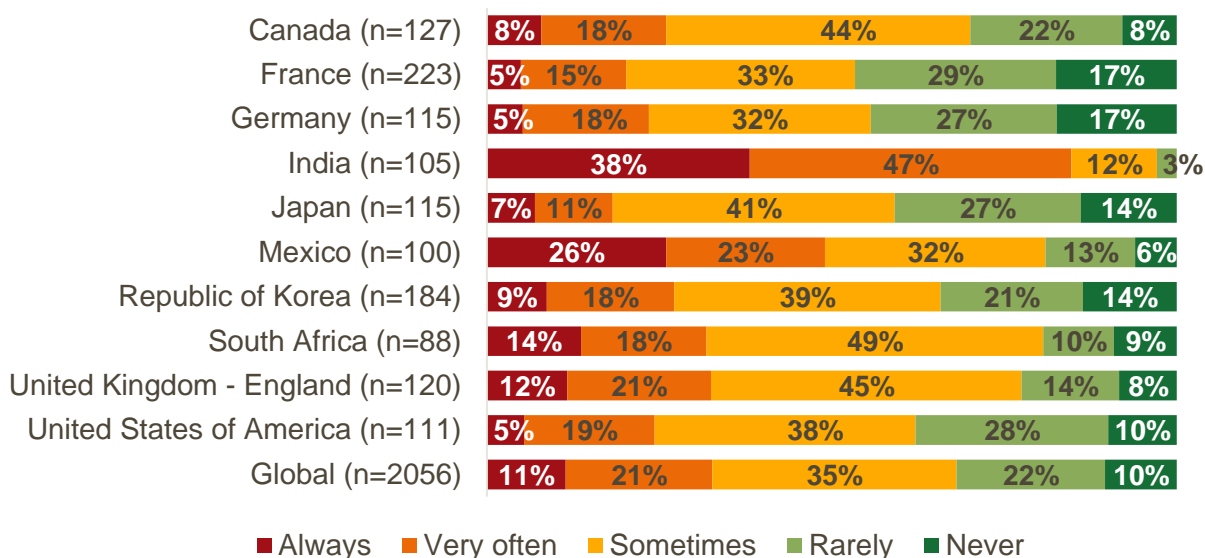


Figure 54. Q24_5 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Sadness or depression by current stage of cancer

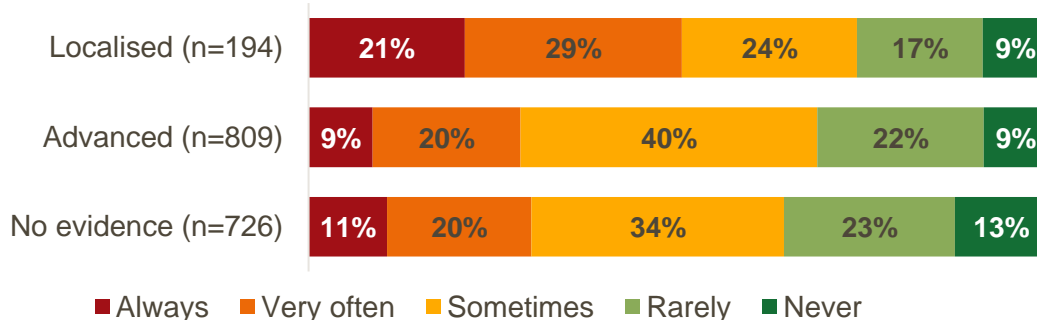
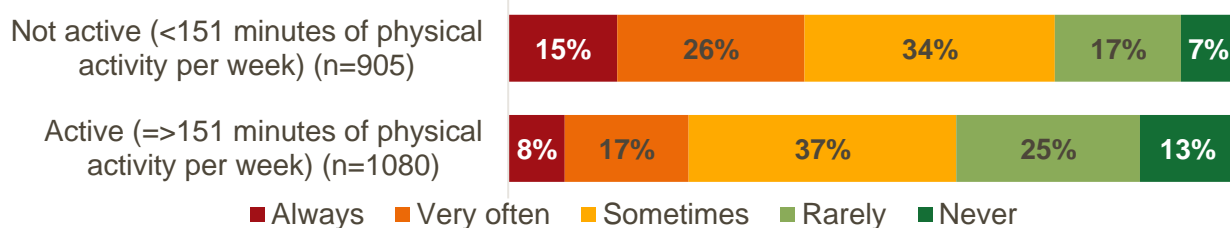


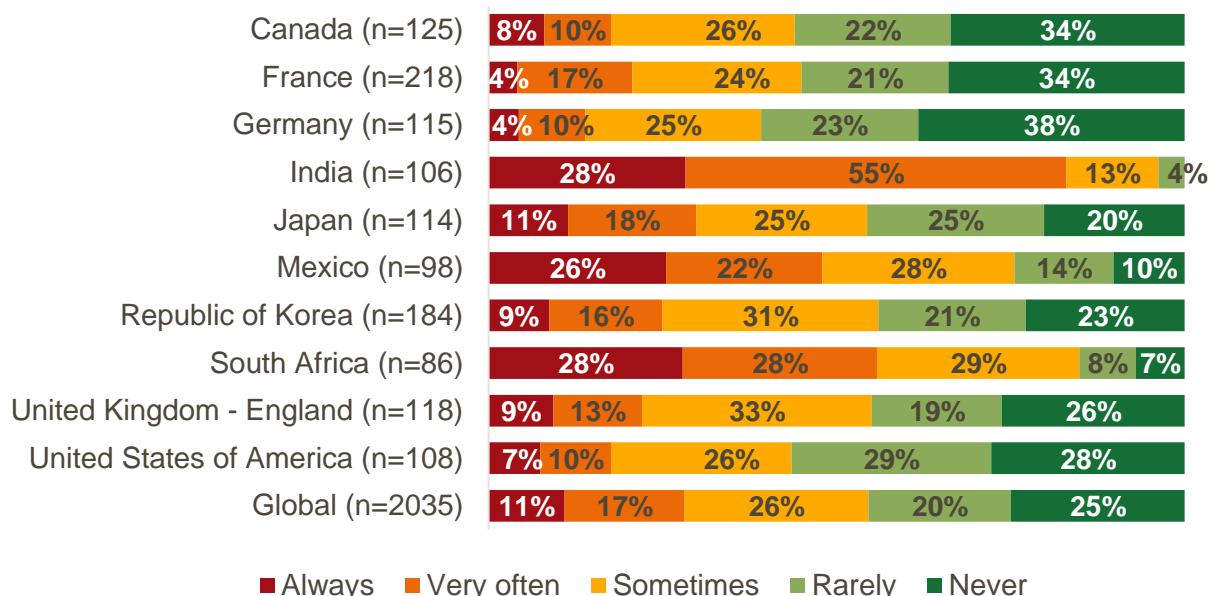
Figure 55. Q24_5 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Sadness or depression by current level of physical activity



Concerns about body image/changes in physical appearance

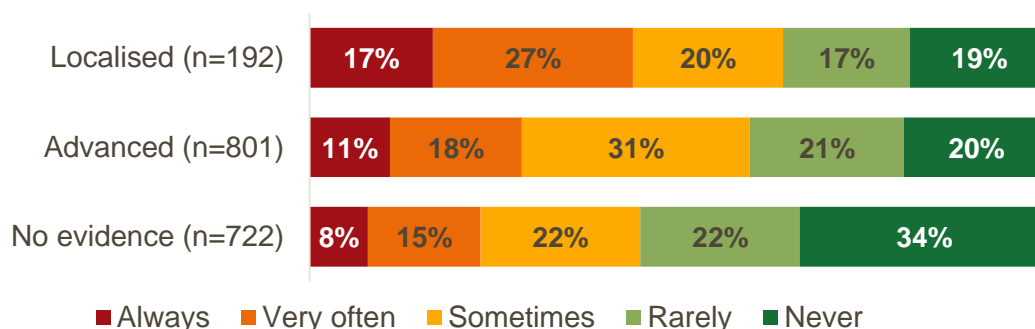
Always experiencing concerns about body image and changes in physical appearance was of most prevalence in India (28%, n=30), South Africa (28%, n=24) and Mexico (26%, n=25). This is compared with 11% (n=222) globally (Figure 56).

Figure 56. 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 by country of residence



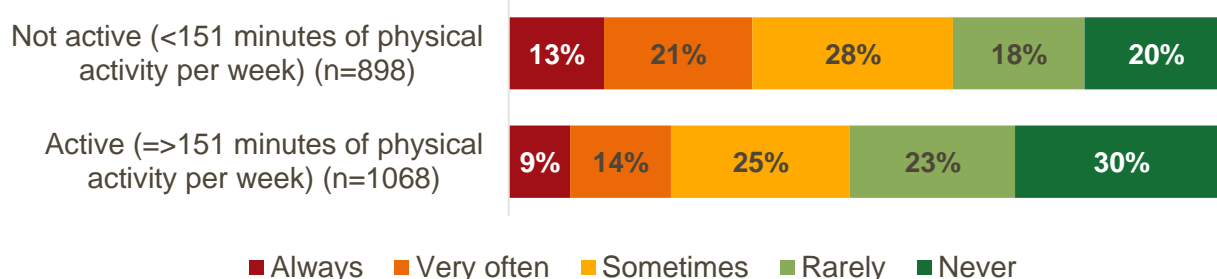
Respondents with no current evidence of disease were more likely to report never experiencing concerns about body image and changes in physical appearance (34%, n=243) than respondents currently at a localised (19%, n=36) and advanced (20%, n=157) cancer stage (Figure 57Error! Not a valid bookmark self-reference.).

Figure 57. 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 by current stage of cancer



More than half of physically active respondents never or rarely experienced concerns about body image and changes in physical appearance (53%, n=561). This is comparable to 38% (n=343) of respondents who are not physically active (Figure 58Error! Not a valid bookmark self-reference.).

Figure 58. 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 by current level of physical activity



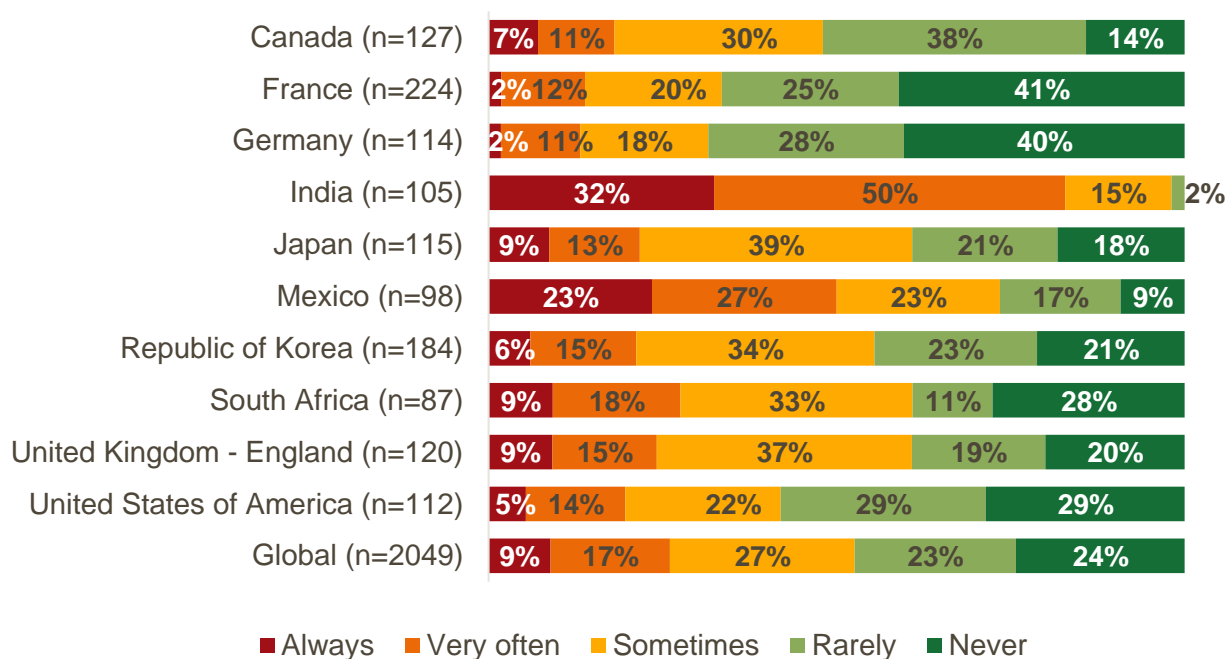
Social and economic wellbeing

In addition to negative impact on physical and emotional wellbeing, a kidney cancer or kidney growth diagnosis can also negatively impact a patient's social and economic wellbeing. The IKCC survey 2022 enquired about the extent to which certain social and economic aspects have impacted patient's sense of emotional wellbeing since their diagnosis.

Isolation

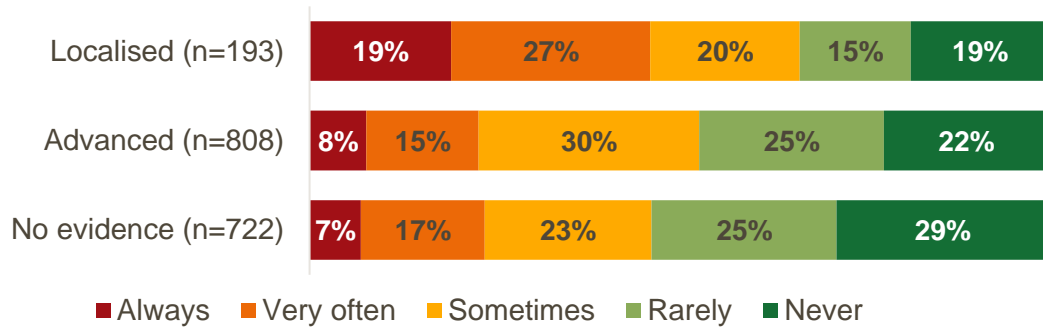
Globally, 9% (n=182) of respondents reported they were always impacted by isolation since their diagnosis. Respondents in India (32%, n=34) and Mexico (23%, n=23) were most likely to report always being impacted by isolation (Figure 59) relative to other countries.

Figure 59. Q24_6 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Isolation by country of residence



Respondents at the localised stage were more than twice as likely to always be impacted by isolation (19%, n=37) than respondents at an advanced stage (8%, n=62) and those without evidence of cancer (7%, n=50) (Figure 60).

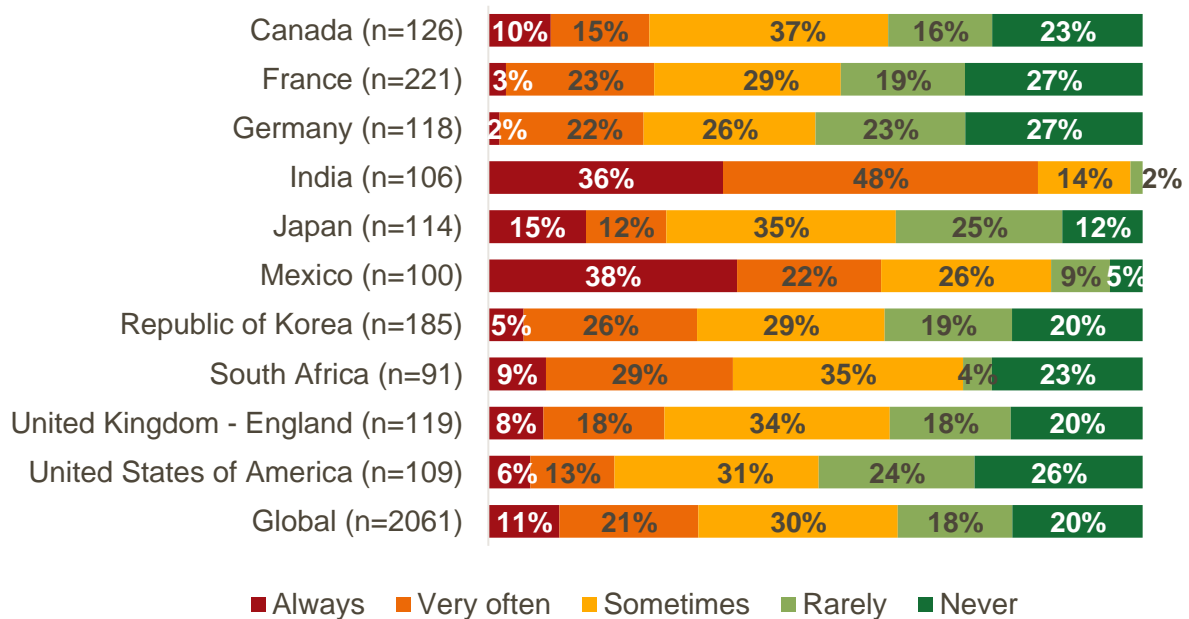
Figure 60. Q24_6 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Isolation by current stage of cancer



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

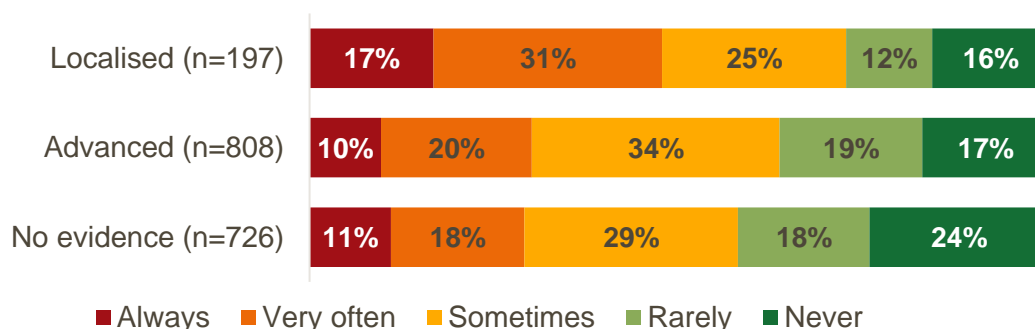
Globally, 11% (n=224) of respondents said changes in relationships with loved ones, friends or co-workers always impacted their sense of emotional wellbeing. Residents in Mexico (38%, n=38) and India (36%, n=38) were more than twice as likely to report they always experienced changes in relationships with loved ones, friends or co-workers than any other country (Figure 61). This contrasts with respondents in Germany (2%, n=2) and France (3%, n=6) who were least likely to report always experiencing changes in relationships.

Figure 61. 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 by country of residence



One in four respondents with no current evidence of disease said changes in relationships with loved ones, friends or co-workers were never a concern for them (24%, n=176). This is compared with 16% (n=31) at a localised stage and 17% (n=138) at an advanced stage (Figure 62).

Figure 62. 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 by current stage of cancer



Difficulty in daily living, on the job or in school

One in three respondents globally reported they always or very often experienced difficulty in daily living, on the job or in school since their diagnosis (34%, n=699). Respondents who were most likely to always or very often be impacted were:

- India (79%, n=84) and Mexico (58%, n=57) residents (Figure 63)
- Respondents at a localised stage of cancer (41%, n=88) (Figure 64)

Figure 63. 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 by country of residence

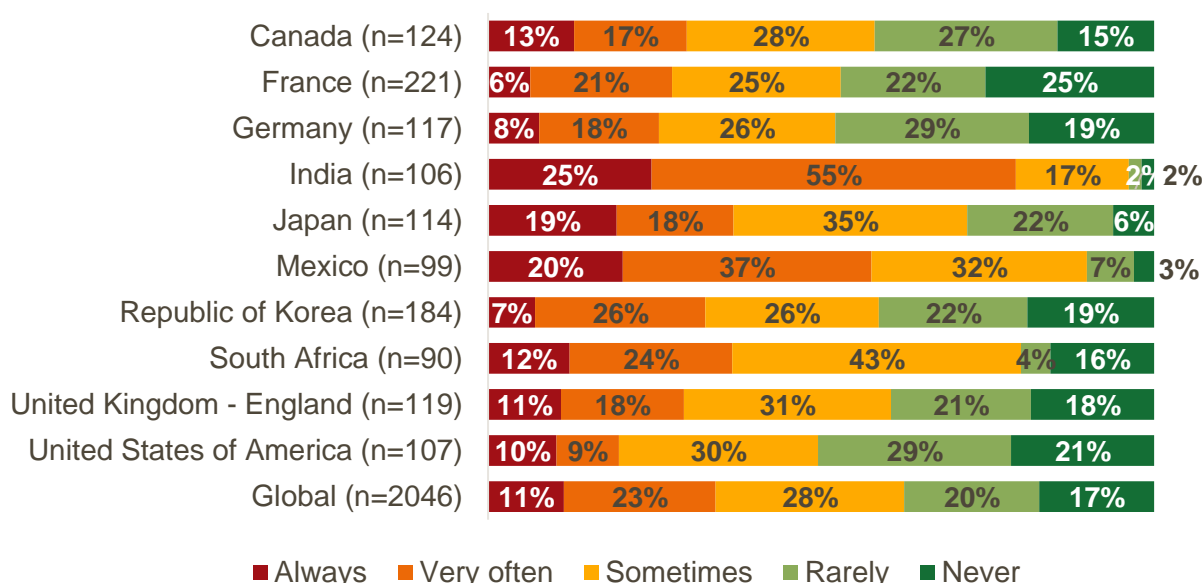
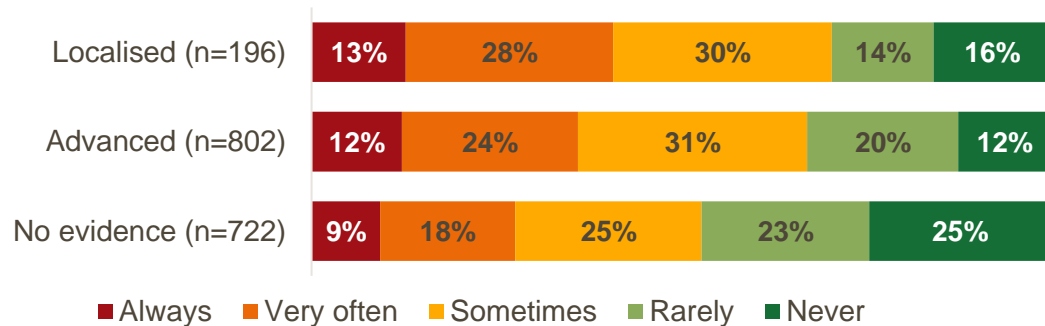


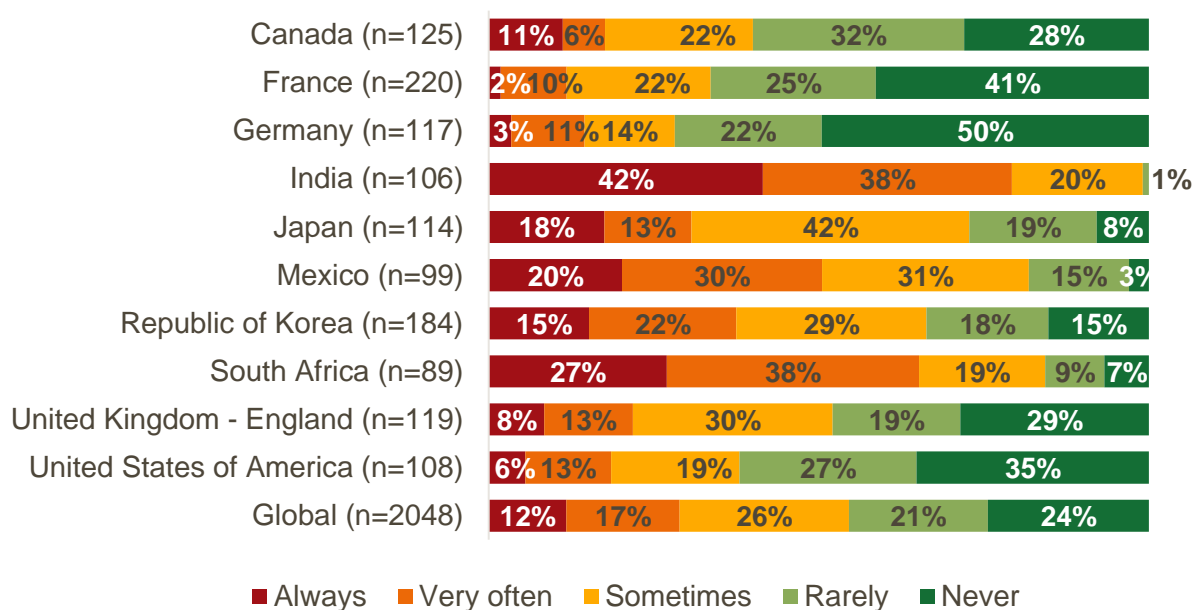
Figure 64. Q25_2 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Difficulty in daily living, on the job or in school by current stage of cancer



Stress related to financial issues

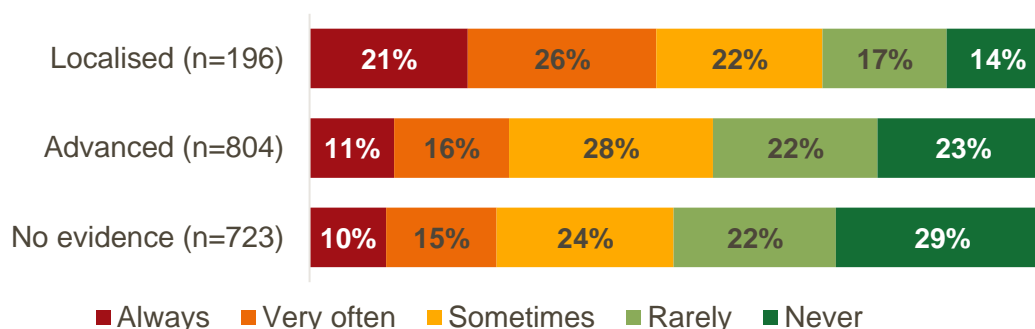
Three in ten respondents globally (29%, n=592) reported they always or very often experience stress related to financial issues since their diagnosis. For a full breakdown by country of residence, see Figure 65.

Figure 65. Q25_3 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Stress related to financial issues by country of residence



Financial stress was of most concern to respondents at the localised stage, with 21% (n=42) of respondents stating they always experienced this impact since their diagnosis. As can be seen in Figure 66, this is notably higher than respondents at the advanced stage (11%, n=92) and no evidence stage (10%, n=75).

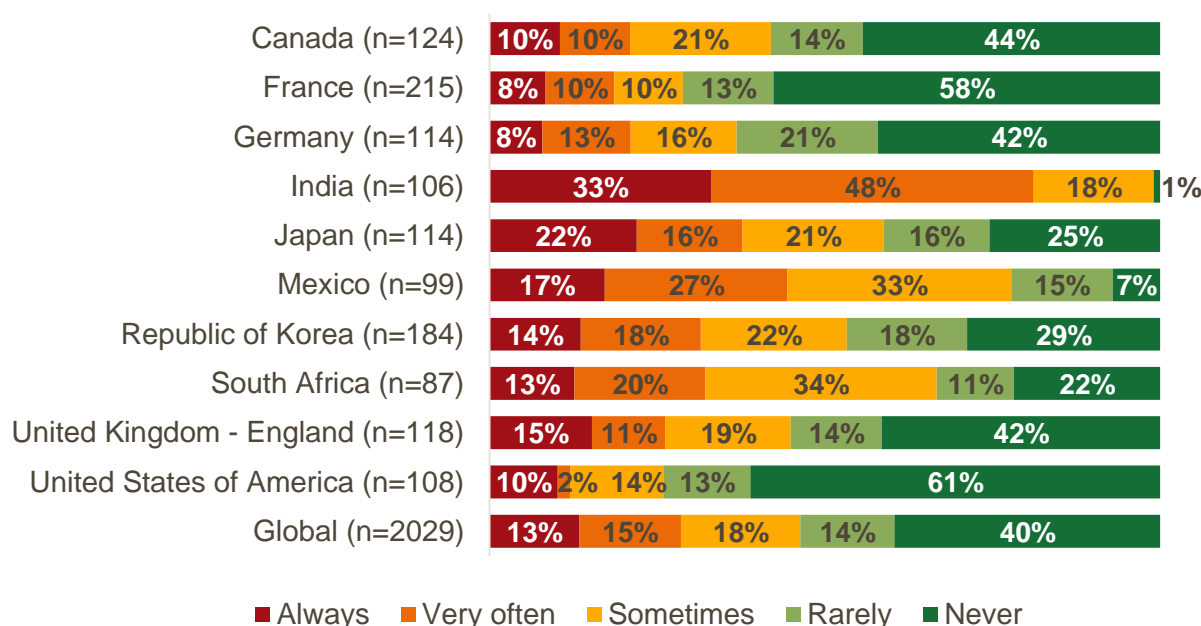
Figure 66. Q25_3 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Stress related to financial issues by current stage of cancer



Loss/reduction in employment

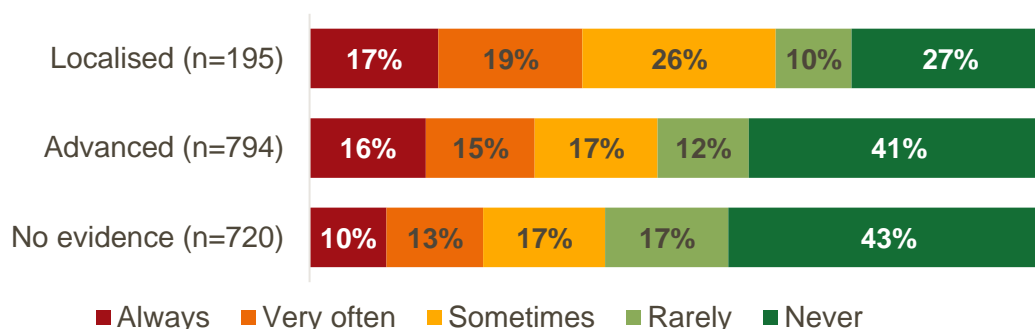
Globally, 4 in 10 respondents (40%, n=804) said loss/reduction in employment was never a concern. Respondents in the USA (61%, n=66) and France (58%, n=124) were most likely to report a loss or reduction in employment was never a concern for them (Figure 67).

Figure 67. Q25_4 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Loss/reduction in employment by country of residence



Respondents at an advanced stage (41%, n=322) and those with no current evidence of cancer (43%, n=312) were more likely to report they have never experienced concerns over loss/reduction in employment since their diagnosis than respondents at a localised stage (27%, n=52) (Figure 68).

Figure 68. Q25_4 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Loss/reduction in employment by current stage of cancer

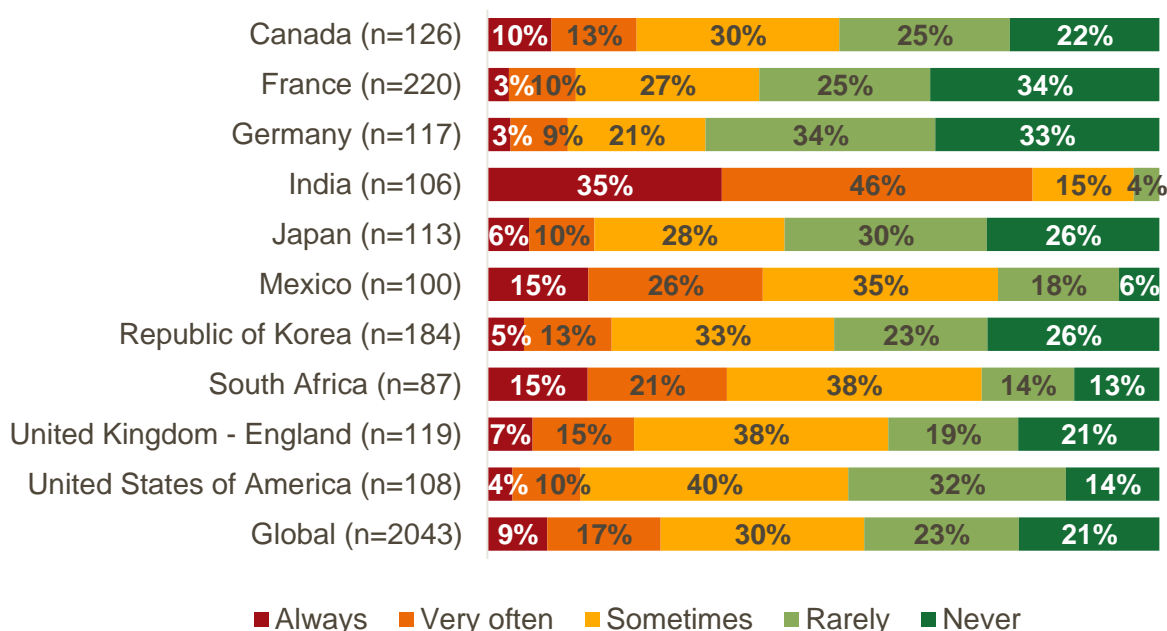


Difficulty navigating the healthcare system

Difficulty navigating the healthcare system always or very often impacted the emotional wellbeing of 1 in 4 respondents globally (26%, n=527) (Figure 69). Countries where this was of greatest concern (always or very often experienced) were:

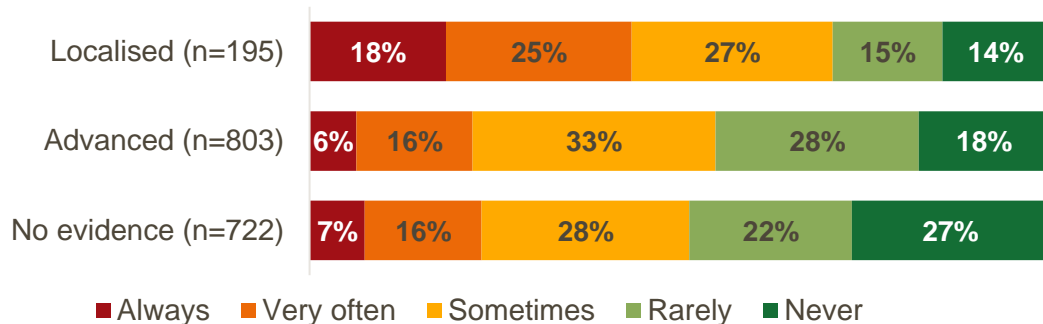
- India (81%, n=86)
- Mexico (41%, n=41)
- South Africa (36%, n=31)

Figure 69. Q25_5 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Difficulty navigating the healthcare system by country of residence



Respondents at a localised current cancer stage (18%, n=36) were more than twice as likely to always experience difficulty navigating the healthcare system than those at an advanced stage (6%, n=51) or those with no current evidence of cancer (7%, n=54) (Figure 70).

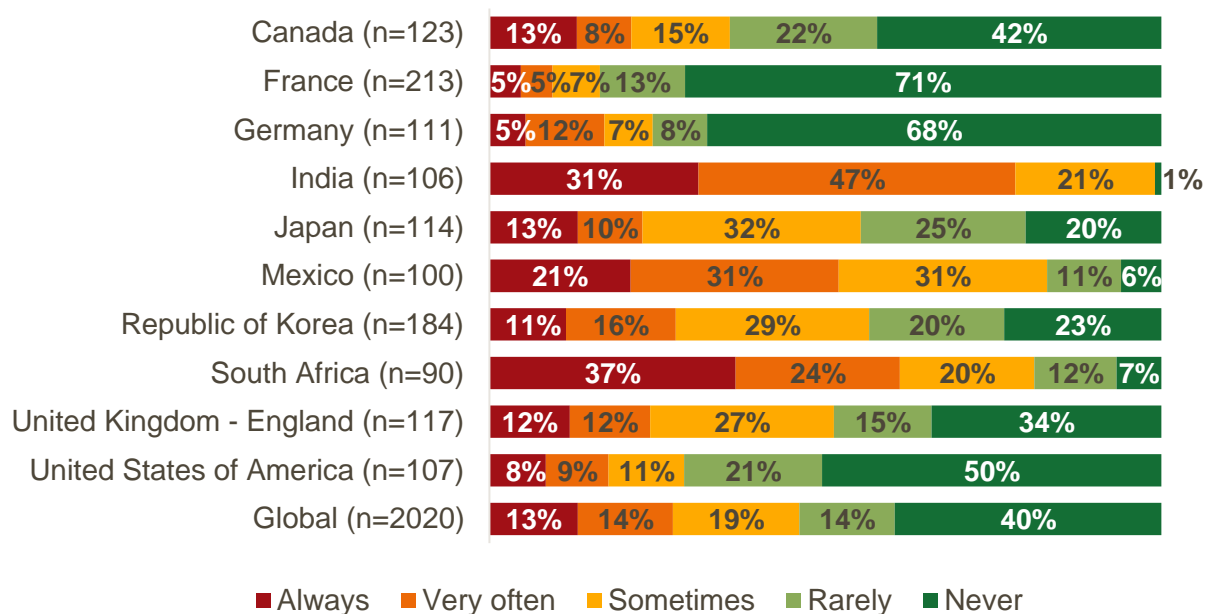
Figure 70. Q25_5 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Difficulty navigating the healthcare system by current stage of cancer



Problems getting health or life insurance coverage

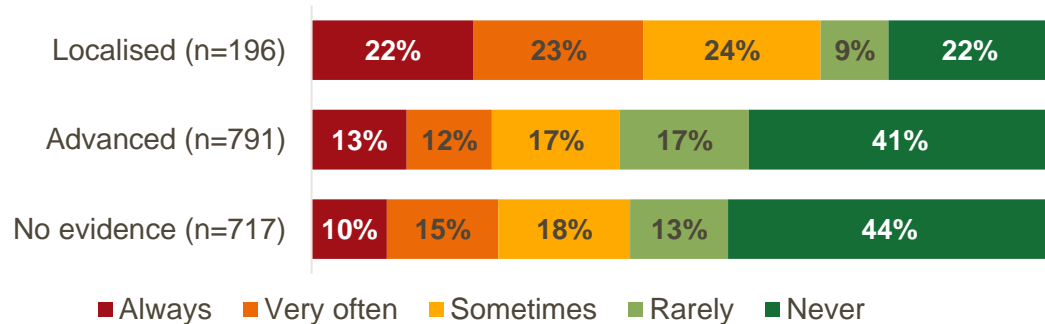
Since their diagnosis, problems getting health or life insurance coverage has never been a concern for 40% (n=801) of respondents globally. This was especially true in France (71%, n=151) and Germany (68%, n=75) (Figure 71). Conversely, problems getting health or life insurance coverage was always a concern for 37% (n=33) of respondents in South Africa and 31% (n=33) of respondents in India.

Figure 71. Q25_6 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Problems getting health or life insurance coverage by country of residence



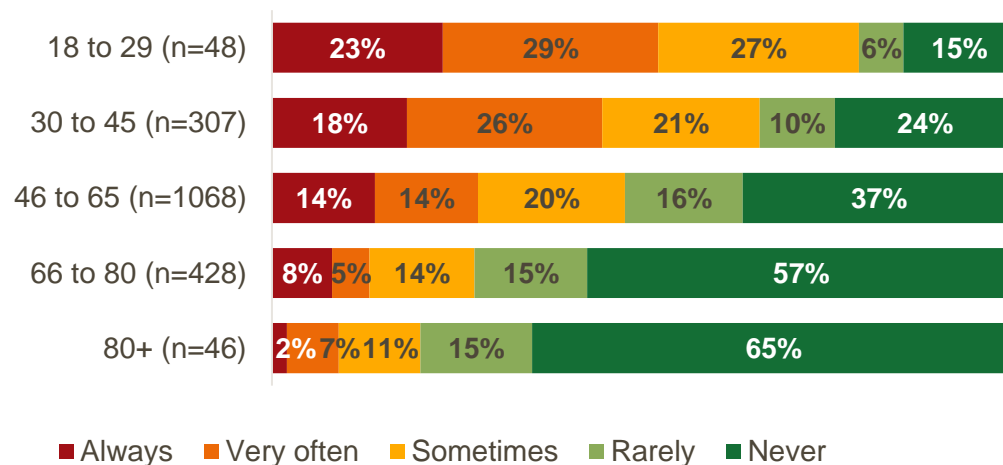
Exploring differences by current stage of cancer revealed respondents at an advanced stage (41%, n=323) or with no current evidence of cancer (44%, n=313) were twice as likely to report they never experienced problems getting health or life insurance coverage than those at a localised stage (22%, n=43) (Figure 72Error! Not a valid bookmark self-reference.).

Figure 72. Q25_6 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Problems getting health or life insurance coverage by current stage of cancer



As shown in Figure 73, 15% (n=7) of respondents aged 18 to 29 reported never experiencing problems getting health or life insurance coverage. However, 44% of patients aged 30 to 45 (n=136) and 28% of patients aged 46 to 65 (n=291) reported they always or very often experienced problems getting health or life insurance coverage.

Figure 73. Q25_6 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Problems getting health or life insurance coverage by age group



Perspectives on Kidney Cancer clinical trials

Awareness of clinical trials

Table 11 outlines the reported experience of survey recipients regarding cancer clinical trial discussions. Globally, 39% (n=790) of respondents reported that no one had discussed clinical trials with them. 41% (n=834) reported either a doctor or a nurse had discussed the topic, while 18% (n=358) indicated that clinical trials had been discussed by a patient organisation or support group. 14% (n=285) had a discussion about clinical trials with their spouse, a friend or family member.

Japan had the highest proportion of respondents who reported that no one had discussed clinical trials with them (62%, n=71), while India had the lowest at just 3% (n=3).

Table 11. Q29 - Who, if anyone, has discussed cancer clinical trials with you? [multiple choice] by country of residence

	Global	Canada	France	Germany	India	Japan	Mexico	Rep. of Korea	South Africa	U.K. England	USA
Base (n=)	2031	127	216	117	106	114	101	175	89	116	107
No one	39%	51%	31%	38%	3%	62%	30%	45%	55%	57%	29%
Doctor / Nurse	41%	34%	52%	36%	62%	18%	48%	31%	29%	30%	64%
Spouse, friend or family	14%	9%	6%	8%	26%	7%	14%	19%	2%	4%	18%
Patient organisation or support group	18%	15%	6%	32%	37%	15%	8%	22%	3%	6%	23%
Other	3%	2%	8%	5%	-	2%	-	2%	1%	4%	1%
Don't know / Can't remember	6%	5%	6%	1%	30%	8%	12%	6%	13%	1%	3%

Taking part in clinical trials

Overall, more than half of respondents globally indicated that they have not been asked to consider participating in a cancer clinical trial (56%, n=1145) (Table 12).

One in five respondents reported a health professional asked them to consider participating in a cancer clinical trial when they were first diagnosed (22%, n=442), while 14% (n=276) were asked when their cancer recurred.

India had the highest proportion of respondents who had been asked to consider participating (62%, n=64), while Japan had the lowest (12%, n=14).

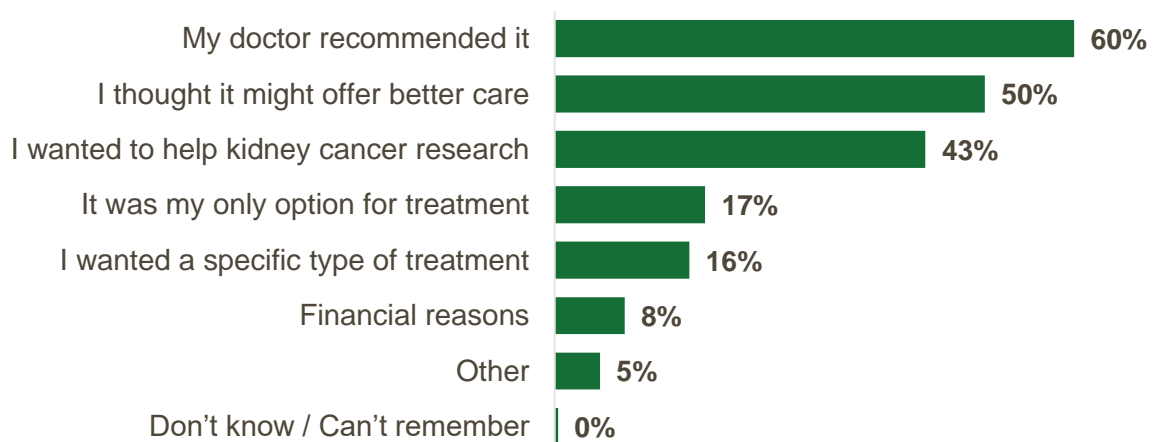
Table 12. Q30 - Have you ever been asked by a health professional to consider participating in a cancer clinical trial? by country of residence

	Global	Canada	France	Germany	India	Japan	Mexico	Rep. of Korea	South Africa	U.K. England	USA
Base (n=)	2032	127	222	118	104	114	102	176	89	117	106
Yes, when I was first diagnosed	22%	21%	29%	11%	39%	6%	32%	16%	18%	21%	33%
Yes, when my cancer recurred	14%	8%	21%	13%	22%	6%	25%	10%	3%	6%	17%
No	56%	65%	45%	69%	10%	86%	25%	69%	48%	70%	46%
Don't know / can't remember	6%	2%	3%	3%	29%	-	13%	3%	22%	1%	4%
I do not know of any clinical trials in my country	3%	5%	2%	3%	-	2%	4%	1%	8%	3%	-

Globally, of those who were invited to consider participating in a cancer clinical trial, 7 in 10 respondents agreed to participate (70%, n=498), 26% (n=189) did not agree and 4% (n=28) did not know or could not remember.

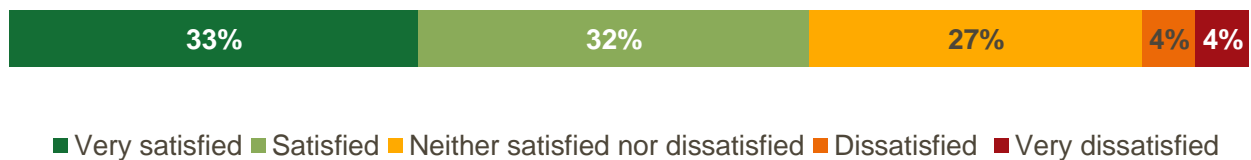
The most commonly cited reason(s) respondents gave for agreeing to participate was because their doctor recommended it (60%, n=297), they thought it might offer better care (50%, n=246) and they wanted to help kidney cancer research (43%, n=212) (Figure 74).

Figure 74. Q32 - Why did you agree to participate? Asked of those who agreed to participate in a trial [multiple choice] (n=496)



As shown in Figure 75, one third of respondents who participated in a cancer clinical trial were very satisfied with their overall experience (33%, n=160). This is compared with just 4% (n=21) who were very dissatisfied with their overall experience.

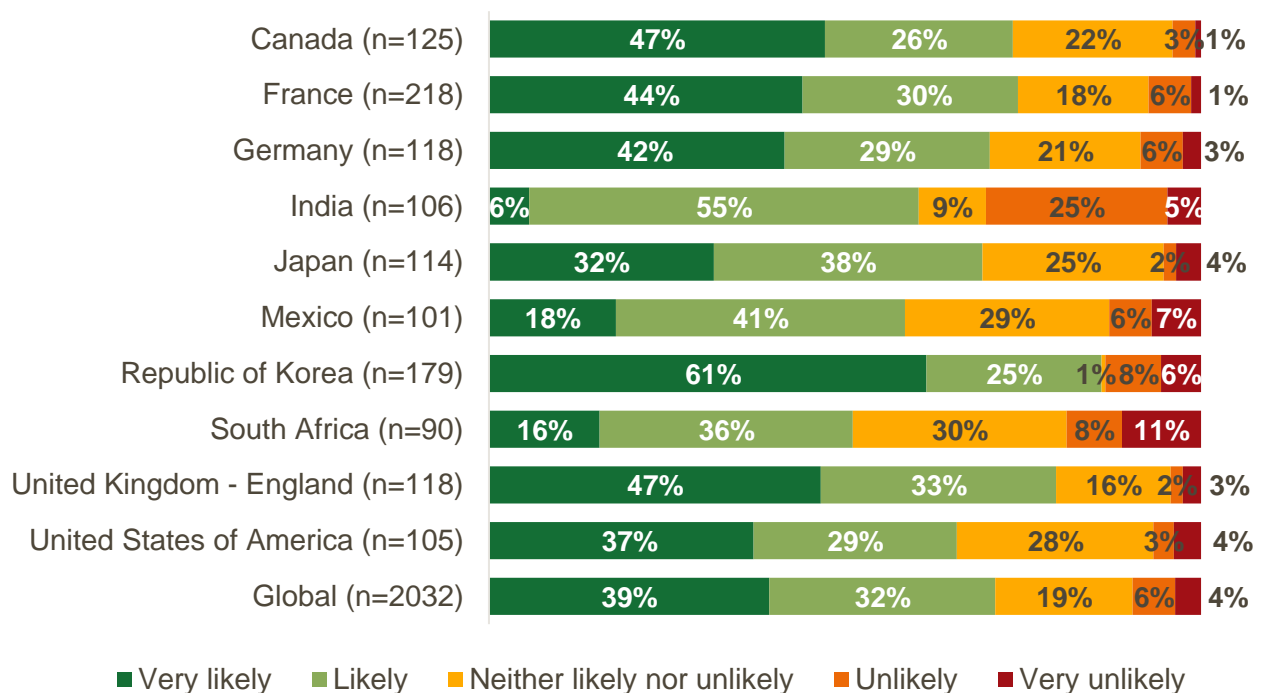
Figure 75. Q33 - How satisfied were you overall with your cancer clinical trial experience?
Asked of those who agreed to participate in a trial (n=485)



All respondents to the survey were asked how likely it is that they would participate in a cancer clinical trial if they were invited in future. As indicated in Figure 76, 71% (n=1445) of respondents globally said it is likely or very likely they would participate. Conversely, 10% (n=195) reported it is unlikely or very unlikely they would participate if invited in future, while 19% (n=392) said it is neither likely nor unlikely.

More than half of respondents in the Republic of Korea said it would be very likely they would participate in future if asked (61%, n=110). This is in stark contrast with India, where just 6% (n=6) of respondents said it would be very likely they would participate.

Figure 76. Q35 - In the future if you were invited, how likely is it that you would participate in a cancer clinical trial? by country of residence



Genetic testing

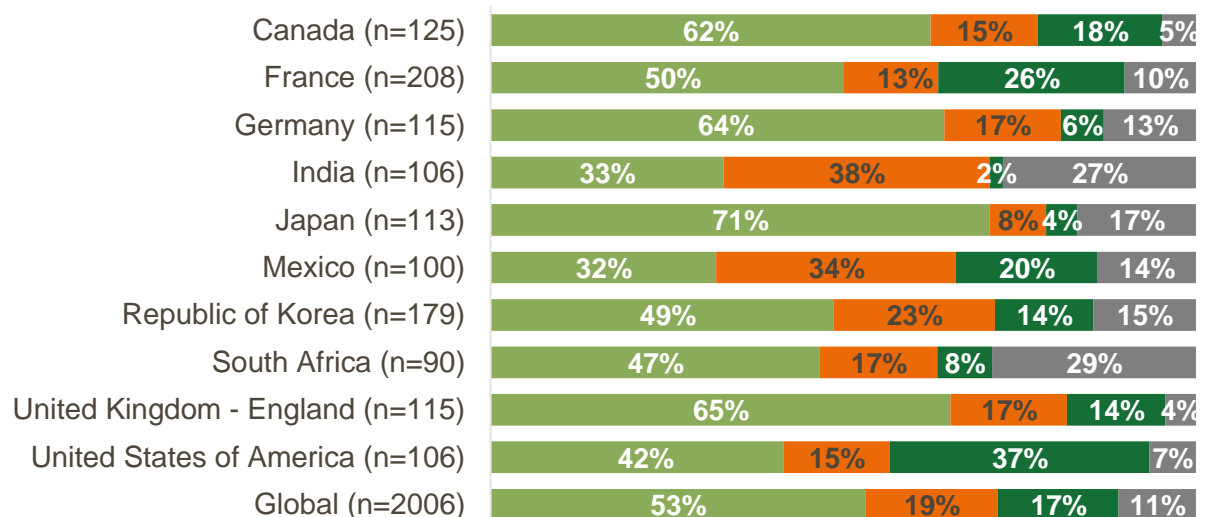
Given increasing awareness of hereditary syndromes that may affect other family members, a new question was added to the survey to explore discussion of possible genetic factors and/or genetic screening.

When asked if a member of the respondent's healthcare team had discussed genetic testing with them, globally:

- 53% (n=1066) said no, as they had none of the relevant risk factors
- 19% (n=377) said they had some of the relevant risk factors, but had not been offered genetic testing
- 17% (n=343) said they had some of the relevant risk factors and were either offered genetic testing or genetic testing had been completed at time of survey
- 11% (n=220) were unsure or couldn't remember

Response by country of residence varied, see Figure 77 for full breakdown.

Figure 77. 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? By country of residence



■ No, I have none of the above risk factors

■ Yes, I have some of the above risk factors but I was not offered genetic testing

■ Yes, I have some of the above risk factors and genetic testing was offered to me / has been completed

■ Unsure/ can't remember

Conclusions

This report presents data 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.

Patient journeys and experience varied significantly by country, but there is clear opportunity for patient organisations and medical professionals to share best practice and approaches to improve patient experience. Some actionable highlights include:

- Willingness to participate in biopsy and active surveillance for small renal masses was high, accounting for two thirds of respondents globally.
- More could be done to communicate the benefits of long-term participation in surveillance following surgery, as the preferred length of surveillance globally was less than two years.
- Further investigation into the circumstances of when genetic testing is discussed and offered would be beneficial to understand and mitigate any existing barriers. 19% of respondents reported they met at least some of the criteria for genetic testing (diagnosed under 46 years old; family history of kidney cancer or bilateral disease) but were not offered genetic testing.
- Patients' lack of understanding of their diagnosis, treatment options, medical care and treatment must be addressed, particularly communicating the likelihood of surviving their cancer beyond five years to all patients in a way that is understood.
- More than half of respondents (52%) indicated they were not as involved as much as they wanted to be in developing their treatment plan. Healthcare providers should ensure they are empowering patients to make informed decisions about their treatment.
- A greater effort should be made to provide emotional support for patients, as only 36% of respondents reported their doctor or healthcare professional was very helpful when they spoke about their concerns.

How results will be used

The IKCC and its global affiliates will use the results to ensure that patient and caregiver voices are heard and acted upon. This information will help patient organisations and medical professionals better understand patients' unmet needs.

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.

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Appendices

1 – List of figures and tables

2 – 2022 International Kidney Cancer Coalition Global Survey Questionnaire

3a and 3b – Global Report Frequency Tables (available as separate documents)

A country-specific report has been written for the 10 countries with the highest responses (93 and above). These are available as separate documents and include:

- France
- Republic of Korea
- Canada
- United Kingdom - England
- Germany
- Japan
- United States of America
- India
- Mexico
- South Africa

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Appendix 2

International Kidney Cancer Coalition Survey 2022

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 patients with kidney cancer or kidney growths everywhere.

Survey instructions

This questionnaire can be answered by anyone who has experience with kidney cancer or kidney growths, whether this is somebody who has received a diagnosis or who is/has been a carer or caregiver to someone with a diagnosis.

This survey will take between 15 and 20 minutes to complete. What you tell us is confidential and taking part is voluntary.

How the results will be used

The information you give us will be used to determine unmet patient needs around the world and to develop, wherever possible, solutions to patient issues. By combining the responses of all participating countries, our aim is to have a better understanding of the geographic variances in patient experience, identify best practices worldwide, and improve our collective understanding of the patient experience.

Thank you for your participation!

Q1 About you

Please describe your experience with kidney cancer and/or kidney growths

- ☐ I have been diagnosed with kidney cancer or a kidney growth
- ☐ I am a carer or caregiver for a loved one who has been diagnosed with kidney cancer or a kidney growth
- ☐ My loved one has died

Thank you for your participation! These questions should be answered from the point of view of the person who has been diagnosed with kidney cancer or a kidney growth.

If you are a carer, caregiver or your loved one has died, please try to answer based on their experience. This includes the following background questions experience.

About you

These questions should be answered from the point of view of the person who has been diagnosed with kidney cancer or a kidney growth.

Q2 What sub-type of kidney cancer do you have?

- ☐ Clear Cell Renal Cell Carcinoma
- ☐ Papillary Renal Cell Carcinoma
- ☐ Chromophobe Renal Cell Carcinoma
- ☐ Unclassified Renal Cell Carcinoma
- ☐ Xp11 Translocation Type
- ☐ VHL (Von Hippel-Lindau syndrome)
- ☐ Renal Medullary Carcinoma
- ☐ Collecting Duct Renal Cell Carcinoma (Bellini Duct)
- ☐ Transitional Cell Carcinoma (Urothelial Carcinoma)
- ☐ Renal Sarcoma (NOT Renal Cell Carcinoma with Sarcomatoid Appearance)
- ☐ Wilms Tumour
- ☐ Benign growth
- ☐ I was not told
- ☐ Don't know / Can't remember
- ☐ Other (Please specify)

Q3 In which country do you currently reside?

[list of 197 countries]

Q4 What was your age at diagnosis?

[Freetext]

Q5 What is your gender?

- ☐ Male
- ☐ Female
- ☐ I prefer to self describe (Please specify)
- ☐ Do not wish to identify

Diagnosis

These questions explore what happened when you were first diagnosed.

Reminder: These questions should be answered from the point of view of the person who has been diagnosed with kidney cancer or a kidney growth.

Q6 In what year were you diagnosed?

[free text]

Q7 Where was your kidney cancer or kidney growth FIRST DIAGNOSED?

- ☐ At my family doctor's office
- ☐ At an emergency department
- ☐ At a community, local or general hospital
- ☐ At a major cancer centre
- ☐ At a major cancer centre by a doctor who specialises in kidney cancer
- ☐ At a private clinic
- ☐ Don't know / Can't remember
- ☐ Other (Please specify)

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

- ☐ Yes
- ☐ No
- ☐ Not sure

Q9 At what stage was the kidney tumour when you were FIRST DIAGNOSED?

- ☐ Tumour was less than 4 cm (1.6 inches) and was just in the kidney without any spread (Stage 1A)
- ☐ Tumour was larger than 4cm (1.6inches) and was just in the kidney without any spread (Stage 1B or Stage 2)
- ☐ Tumour had spread locally outside of the kidney (Stage 3)
- ☐ Tumour had spread to other organs or sites (Stage 4)
- ☐ I was not told
- ☐ Don't know / Can't remember
- ☐ Other (Please specify)

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

- ☐ Less than 1 month
- ☐ 1 – 3 months
- ☐ 3 - 6 months
- ☐ 6 months - 12 months
- ☐ More than 12 months
- ☐ Don't know / Can't remember

Q11 When planning your treatments, were the following explained in a way you could understand?

	Yes, completely	Yes, to some extent	No, this was not explained	I did not need an explanation	Don't know / can't remember
Stage of cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sub-type of cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Treatment options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Treatment recommendations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Risk of recurrence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Likelihood of surviving your cancer beyond five years	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q12 Did you ever seek a second opinion about your kidney cancer?

- ☐ Yes
- ☐ This was not available to me
- ☐ No, I have never considered it
- ☐ No, this was not necessary

Developing a treatment plan

These questions are about developing your treatment plan.

When answering please think about the development of your most recent treatment plan.

Q13 Were you involved as much as you wanted to be in decisions about your treatment plan?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No
- ☐ I did not want to be involved
- ☐ Don't know / Can't remember

Q14 Who or what else helped you make decisions about your treatment plan? (PLEASE CHOOSE ALL THAT APPLY)

- ☐ My partner / spouse
- ☐ My parents
- ☐ My children
- ☐ My friends / other family members
- ☐ My family doctor
- ☐ A patient organisation or support group
- ☐ Online resources
- ☐ ☒ It was my decision alone
- ☐ My personal financial situation
- ☐ ☒ Don't know / Can't remember
- ☐ Other (Please specify)

Your care and treatment

This question explores your experiences of care and treatment overall

Q15 Which barriers (if any) have you experienced that affected your treatment choices for your kidney cancer or kidney growth? (PLEASE CHOOSE ALL THAT APPLY)

- ☐ Cost of treatment
- ☐ Lack of access to treatment centre/prohibitive travel
- ☐ Language/inability to understand the treatment
- ☐ Lack of access to the most up-to-date treatment or equipment
- ☐ Wait time to treatment was an issue for me
- ☐ Lack of personal support
- ☐ No speciality doctor locally
- ☐ Difficulty managing my carer/caregiver role (child, parent, disabled person) while in treatment
- ☐ Fear of discrimination if my employer/friends/family knew about my disease
- ☐ No available treatments
- ☐ ☒ I experienced no barriers
- ☐ Other barrier not mentioned above

Your care today

These questions consider your situation and care experiences today.

Q16 Which of the following best describes your stage of kidney cancer or kidney growth TODAY?

- ☐ I currently have no evidence of disease
- ☐ I was told that I am cured
- ☐ Kidney cancer / growth is still only within the kidney (Stage 1 or Stage 2)
- ☐ Kidney cancer / growth is still locally advanced (Stage 3)
- ☐ Kidney cancer / growth has spread to other organs or distant sites (Stage 4)
- ☐ Don't know / Can't remember
- ☐ Other (Please specify)

Q17 Where are you CURRENTLY being treated or followed?

- ☐ At a community, local or general hospital
- ☐ At a major cancer centre
- ☐ At a private clinic
- ☐ I am not currently being treated or followed anywhere
- ☐ Other (Please specify)

Q18 Do you understand the following?

	Yes	Yes, to some extent	No	N/A
Surgical options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Immunotherapy options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Targeted therapy options (pills or tablets)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Radiation therapy options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ablative therapy options (cryoablation or radiofrequency ablation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Active surveillance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adjuvant therapy (treatment aimed at reducing the chance of recurrence after surgery)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q19 Do you understand the following?

	Yes	Yes, to some extent	No	N/A
Palliative/ supportive care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The importance of good nutrition for my well-being	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The importance of lifestyle choices for my wellbeing (e.g. avoiding smoking, being active)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Complementary therapies (e.g. meditation, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My local guidelines for kidney cancer care and follow up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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?

- ☐ Yes
- ☐ No
- ☐ Don't know

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?

- ☐ Yes
- ☐ No
- ☐ Don't know

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?

- ☐ Less than 2 years
- ☐ 2 to 4 years
- ☐ 4 to 6 years
- ☐ More than 6 years
- ☐ Don't know
- ☐ I would decide based on my healthcare team's opinion

Quality of life

These questions explore your understanding of quality of life and the availability of sources of support.

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)
- ☐ Not very active (101-150 minutes of physical activity per week)
- ☐ Within physical activity guidelines (151-300 minutes of physical activity per week)
- ☐ Above physical activity guidelines (≥ 300 minutes of physical activity per week)
- ☐ Prefer not to answer

Q24 How often have the following impacted your sense of emotional well-being since your diagnosis?

	Always	Very often	Sometimes	Rarely	Never
General anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disease-related anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fear of dying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fear of the cancer/growth coming back (recurrence)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sadness or Depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Isolation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q25 How often have the following impacted your sense of emotional well-being since your diagnosis?

	Always	Very often	Sometimes	Rarely	Never
Changes in relationships with loved ones, friends or co-workers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty in daily living, on the job or in school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stress related to financial issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss/reduction in employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty navigating the healthcare system	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Problems getting health or life insurance coverage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Concerns about body image/changes in physical appearance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q26 Is there anything else related to your diagnosis that has affected your emotional well-being?

[free text]

Q27 Have you ever talked to your doctor or to any other healthcare professional about any of your concerns?

- ☐ Yes, they were very helpful
- ☐ Yes, they were somewhat helpful
- ☐ Yes, but they were not helpful
- ☐ I did not raise any concerns with a doctor or other healthcare professional
- ☐ Don't know / Can't remember

Q28 Have you ever used a patient support group (either in person or online) to help you with your kidney cancer / growth?

- ☐ Yes
- ☐ No
- ☐ Don't know / Can't remember

Cancer Clinical Trials

These questions explore your understanding of cancer clinical trials.

Q29 Who, if anyone, has discussed cancer clinical trials with you? (PLEASE CHOOSE ALL THAT APPLY)

- ☐ ☒ No one
- ☐ Doctor / Nurse
- ☐ Spouse, friend or family
- ☐ Patient organisation or support group
- ☐ Other (Please specify)
- ☐ ☒ Don't know / Can't remember

Q30 Have you ever been asked by a health professional to consider participating in a cancer clinical trial?

- ☐ Yes, when I was first diagnosed
- ☐ Yes, when my cancer recurred
- ☐ No
- ☐ Don't know / can't remember
- ☐ I do not know of any clinical trials in my country

Q31 Did you agree to participate in the cancer clinical trial?

- ☐ Yes
- ☐ No
- ☐ Don't know / Can't remember

Q32 Why did you agree to participate? (PLEASE CHOOSE ALL THAT APPLY)

- ☐ My doctor recommended it
- ☐ I thought it might offer better care
- ☐ I wanted a specific type of treatment
- ☐ It was my only option for treatment
- ☐ I wanted to help kidney cancer research
- ☐ Financial reasons
- ☐ ☒ Don't know / Can't remember
- ☐ Other

Q33 How satisfied were you overall with your cancer clinical trial experience?

- ☐ Very satisfied
- ☐ Satisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Dissatisfied
- ☐ Very dissatisfied

Q34 Please explain why you rated your cancer clinical trial experience this way.

[free text]


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

- ☐ Very likely
- ☐ Likely
- ☐ Neither likely nor unlikely
- ☐ Unlikely
- ☐ Very unlikely

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?

- ☐ No, I have none of the above risk factors
- ☐ Yes, I have some of the above risk factors but I was not offered genetic testing
- ☐ Yes, I have some of the above risk factors and genetic testing was offered to me / has been completed
- ☐ Unsure/ can't remember



Picker Institute Europe
Suite 6, Fountain House,
1200 Parkway Court,
John Smith Drive,
Oxford OX4 2JY

Tel: +44 (0) 1865 208100

info@pickereurope.ac.uk
picker.org

Charity registered in England and Wales: 1081688

Charity registered in Scotland: SC045048

Company limited by guarantee registered in England and Wales: 3908160