



# International Kidney Cancer Coalition Global Survey 2020

Global Report

July 2021

**Prepared by:** Picker for the  
International Kidney Cancer Coalition



## 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

Foundation, registered in The Netherlands under: Stichting International Kidney Cancer Coalition | Registered No KvK 62070665 | Website: <https://ikcc.org/>

## Picker

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

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

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## Foreword

The 2020 IKCC Global Patient survey involved the preparation and distribution of surveys to patients with kidney cancer and their caregivers in 13 languages through IKCC's participating Affiliate Organisations and social media, resulting in >2000 responses from 41 countries around the world. This was our second biennial survey, following our inaugural survey in 2018. We aimed to identify best practices, key issues for more timely topics, and trends in key patient indicators such as shared decision making, clinical trials and quality of life both globally and by country. Country reports are being prepared for any country exceeding 100 respondents, as well as a Global Report, a roll up of all responses to present a worldwide picture.

Please note that a limitation of this survey is that it was promoted by patient advocate organisations, and therefore has an inherent bias towards including individuals associated with a patient organisation, and may, for example, underrepresent individuals who have died from their disease. Furthermore, because the COVID-19 pandemic intervened between the 2018 and 2020 surveys, it is difficult to make direct comparisons between the two survey results, as some countries could not participate this time due to impact of COVID-19. Nevertheless, some of the results found in the 2020 survey do reinforce trends observed from the 2018 survey, despite the pandemic effect, including psychosocial impact, understanding of diagnosis, and views on clinical trials.

In this current survey, we have added 3 new areas of inquiry, generating novel data about global views on:

- Biopsy
- Patient Activation
- Physical Activity

We thank everyone involved with the development of this survey: the participating patient organisations, the individuals who took their time to fill it in, the experts involved at all levels, Picker Institute, and especially those involved in the multinational steering committee who reviewed multiple iterations of this questionnaire and report.

Sincerely,

Dr. Rachel Giles

Chair, International Kidney Cancer Coalition

## Executive summary

Kidney cancer is a global issue. Every year, an estimated 431,000 people worldwide are diagnosed with the disease<sup>1</sup>. The diagnosis of kidney cancer and other renal masses is on the rise globally and presents an increasing burden on health systems, governments, and most of all to individual patients and their families. Although therapies have improved for both early-stage and late-stage Renal Cell Carcinoma (RCC) patients, little is known about the variances in patient experience from country to country, including unmet needs and best practices in patient education, quality of life, and involvement in clinical trials and registries.

To improve collective understanding, the International Kidney Cancer Coalition (IKCC) established a biennial global survey 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 includes understanding:

- Patient knowledge, expectations of treatment and shared decision making
- Clinical trials, research awareness and sources of information
- Quality of life and overall health status of respondents

The 2020 survey also included special areas of inquiry including:

- Biopsy practice: experience and willingness to repeat in the future
- Physical activity: to what extent do patients undertake physical activity as part of their overall survivorship?
- Patient Health Engagement Scale (PHE-S): to what extent do patients make sense of their health status and their perceived role in the healthcare journey?

The survey was published online in 13 languages and promoted through IKCC affiliates and partners, as well as via the IKCC social media and web pages.

This report details the findings from this survey, which ran between October 2020 and January 2021. It is supplemented with country-specific reports (where respondent numbers allow), as well as an online dashboard to further interrogate the results.

The results in this report present the global data from all worldwide respondents.

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<sup>1</sup> Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A (2018). Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality world-wide for 36 cancers in 185 countries. *CA Cancer J Clin.* 68(6):394–424.

Overall number of responses **2,012** from a total of **41 countries**. Comprised of:



**1,586** patients



**417** carers or caregivers

**9** undisclosed

**Table 1: Q1 - Please describe your experience with kidney cancer and/or kidney growths (n=2012)**

Country	I have been diagnosed with kidney cancer or a kidney growth	I am a carer or caregiver to someone who has been diagnosed with kidney cancer or a kidney growth	My loved one has died	Undisclosed
United States of America (n=321)	267	46	8	-
South Korea (n=300)	185	101	14	-
Canada (n=241)	205	24	10	2
France (n=234)	200	16	18	-
India (n=163)	116	42	4	1
Japan (n=156)	143	12	1	-
United Kingdom - England (n=149)	138	6	5	-
Spain (n=50)	23	26	-	1
Australia (n=46)	37	8	1	-
Germany (n=39)	33	2	3	1
Italy (n=28)	14	12	2	-
Sweden (n=25)	22	3	-	-
Brazil (n=25)	16	8	1	-
Netherlands (n=17)	15	1	1	-
Portugal (n=13)	11	-	1	1
United Kingdom - Scotland (n=11)	11	-	-	-
Other (n=70)	59	11	-	-
Unspecified (n=124)	91	24	6	3
<b>Global</b>	<b>1,586</b>	<b>342</b>	<b>75</b>	<b>9</b>

The following pages outline some of the key global findings: (For full results, please see [Appendix 2](#)).

## Patient knowledge, expectations of treatment and shared decision making:

Time to diagnosis – see page 16



**74%** of respondents reported that it was less than 3 months between their first thinking that there might be something wrong to when they were correctly diagnosed.

Shared decision making – see page 26



**51%** of respondents reported that they were definitely involved as much as they wanted to be in developing their treatment plan.

Understanding of diagnosis – see page 17



**88%** of respondents completely or to some extent understood 'treatment options', at diagnosis.

**88%** felt that 'treatment recommendations' were completely/to some extent understood at diagnosis.

**42%** reported that the likelihood of surviving their cancer beyond five years was not explained.

Barriers to treatment – see page 28



**56%** of respondents reported experiencing barriers to treatment.

Biopsy – see page 34



**45%** of respondents reported that they had a biopsy (30% of the kidney; 15% of other sites)

**3%** were offered a biopsy but refused the procedure

## Clinical trials, research awareness and sources of information:

Awareness of clinical trials – see page 41



**46%** of respondents indicated that “No one” discussed cancer clinical trials with them.

Experience of clinical trials – see page 42

**31%** of respondents were invited to take part in a clinical trial.



**67%** of those who took part in a clinical trial were satisfied with their experience overall.

**8%** were dissatisfied with their clinical trial experience

## Quality of life and overall health status of respondents:

Level of physical activity – see page 45



**46%** of respondents self-reported that they were insufficiently active or completely sedentary

Psychosocial wellbeing – see page 49

**49%** of respondents indicated that they ‘very often’ or ‘always’ experienced disease-related anxiety.



**26%** of respondents ‘very often’ or ‘always’ experienced stress related to financial issues.

**55%** of respondents indicated that they ‘very often’ or ‘always’ experienced a fear of recurrence.

Seeking support – see page 70



**52%** of respondents reported having talked to their doctor / healthcare professional about their concerns.

## 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 2020 biennial Global Patient Survey targeted at patients with kidney cancer or a kidney growth, their carers or caregivers.

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 practices, and to empower patient organisations with information that 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 intend 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.

This report outlines the methods and results from the 2020 Global Survey, administered by Picker on behalf of the IKCC.

# Methodology

## 2020 Questionnaire development

Following a review of the 2018 survey findings and consultation with IKCC Affiliate Organisations and the IKCC Medical Advisory Board, the survey instrument was updated to include specific topics that would potentially be actionable to improve patient care. Specific topics added included:

- Biopsy
- Physical activity
- Patient activation

In total, the survey covered the following core areas:

- **Patient knowledge, expectations of treatment and shared decision making**

*To what degree have patients been made aware of and have an understanding of their diagnosis, including stage, subtype, treatment options, and expected side effects?*

- Of those who did not understand their disease, who are they and how can they be reached?
- What are patient's primary sources of information? What is missing?
- What are patient's expectations for treatment? For side effects?
- To what degree are patients involved in making treatment decisions (Shared Decision Making)? Who else is involved and to what degree?
- Are patients receiving biopsies and to what extent would they be willing to receive one in the future?

- **Clinical trials, research awareness and sources of information**

*To what extent are patients made aware of potential advancements in care (including surgical advances, immunotherapy, targeted treatments, radiation therapy, and palliative care, and what are their expectations?*

- Have any healthcare professionals discussed clinical trials with patients?
- Have patients enrolled (if No, what were the reasons/barriers; if Yes, what were the reasons)
- What are patient's sources of information for clinical trials?
- What are patient's expectations for clinical trials?

○ **Quality of life and overall health status of respondents**

*What are respondents' current levels of physical activity and what psychosocial burdens are patients living with, and how do these issues affect their day to day lives?*

- To what extent do patients undertake physical activity as part of their overall survivorship?
- What are patient psychosocial and emotional wellbeing needs?
- What are the unmet needs to support patient's goals for Quality of Life (QoL)?
- Which patients are not seeking help/support? Why?
- To what extent have patients made sense of their health status and their perceived role in the healthcare journey?

The survey also 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.

The English (UK) questions were translated into 12 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) | ○ Polish     |
| ○ Dutch                | ○ German            | ○ Portuguese |
| ○ English (UK)         | ○ Hindi             | ○ Spanish    |
| ○ English (US)         | ○ Japanese          |              |
| ○ French               | ○ Korean            |              |

Before launch, the complete survey was tested for readability and useability by the IKCC via their global affiliates.

## 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 29 October 2020 and 5 January 2021. 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.

During the fieldwork period there was the worldwide global pandemic, COVID-19. important to note, this may have affected response rates, and might have influenced how people responded to the survey questions.

## Analysis and reporting

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. This ensured that respondents were only shown questions that were relevant to them. For example: Q27: “Have you ever been invited to participate in a cancer clinical trial?”. Only respondents that answered “Yes” to this question, were directed to Q28: “Did you agree to participate in the cancer clinical trial?”.

Consequently, some questions were only asked of a subset of respondents. Furthermore, respondents had the ability to leave questions blank. This means that the total number of respondents may fluctuate between questions. Where applicable the total number of respondents, or base size, is indicated with the abbreviation n.

### 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\_RecaptureScore<sup>2</sup>. Any suspect data were analysed for potential ballot box stuffing through repeated entry. 325 responses were deleted as they did not meet the inclusion criteria.

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<sup>2</sup> 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.

## 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 subtype
- year of diagnosis
- cancer stage at diagnosis
- cancer stage at time of response
- age
- gender
- respondent subtype (patient/caregiver)

Please note, for any sub-group analyses, 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.

Where there were over 100 responses from a particular country, a country-specific report has been written. These are available as separate documents and include:

- Canada
- France
- India
- Japan
- South Korea
- United Kingdom - England
- United States of America

## Derived questions

In the interest of accuracy and ensuring that the results are representative, derived questions have been used when reporting feedback, where necessary.

Some questions were not applicable to all respondents but were not proceeded 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 removing these 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+.

### Example: Derived questions

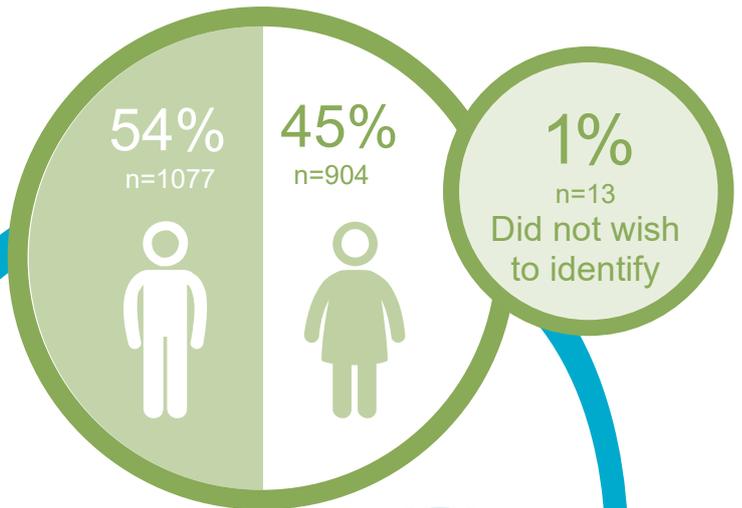
Q8 - WHEN YOU WERE FIRST CORRECTLY DIAGNOSED, were you told what subtype of kidney cancer or kidney growth you had?				Q8+ - WHEN YOU WERE FIRST CORRECTLY DIAGNOSED, were you told what subtype of kidney cancer or kidney growth you had?			
Yes...	852	42%		Yes...	852	48%	
No...	909	46%		No...	909	52%	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

Full frequency tables can be found in Appendix 2.

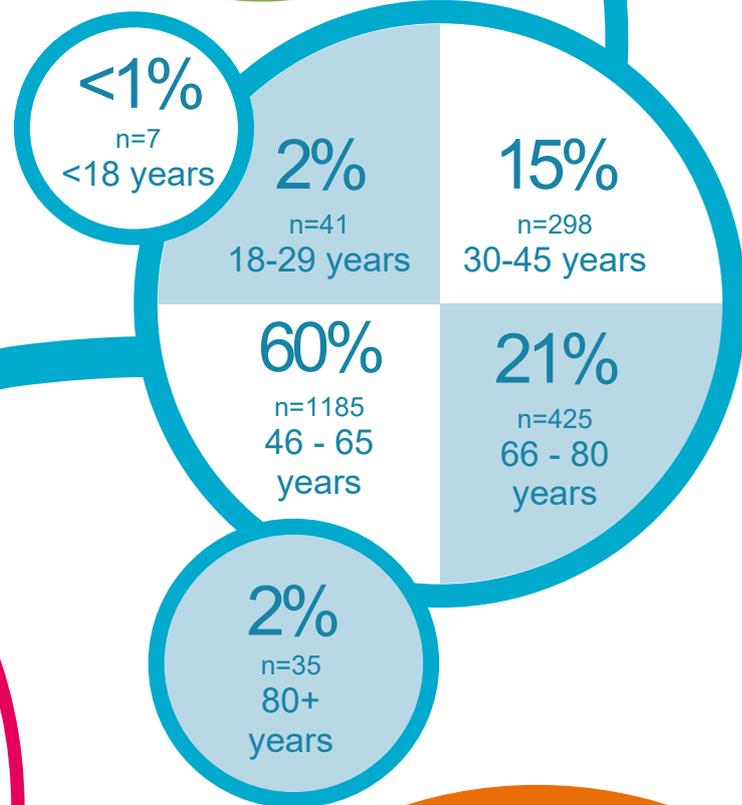
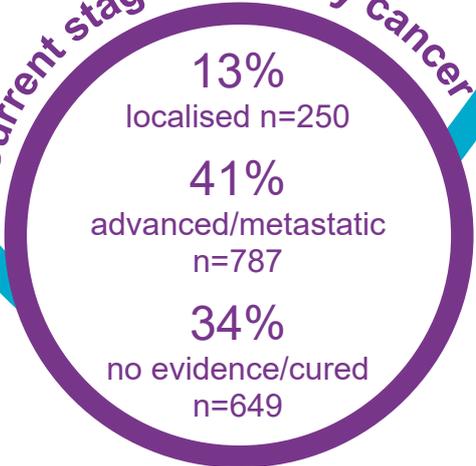
## Data presentation

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%.

## Global survey activity



### Current stage of kidney cancer



### Kidney cancer subtype

Clear Cell Renal Cell Carcinoma	64%
Papillary Renal Cell Carcinoma	9%
Chromophobe Renal Cell Carcinoma	6%
Unclassified Renal Cell Carcinoma	2%
VHL (Von Hippel-Lindau syndrome)	1%
Benign growth	1%
Transitional Cell Carcinoma	1%
Xp11 Translocation Type	1%
Wilms Tumour	1%
Renal Sarcoma	<1%
Renal Medullary Carcinoma	<1%
Collecting Duct Renal Cell Carcinoma	<1%
I was not told	3%
Other	4%
Don't know / Can't remember	6%

### Year of diagnosis

Prior to 2008	10%
2008-2010	8%
2011-2013	10%
2014-2016	19%
2017-2019	40%
2020-present	14%
Don't know / Can't remember	0%

## Patient knowledge, expectations of treatment and shared decision making

Fast access to reliable health advice; clear information, communication, and support for self-care as well as involvement in decisions; and respect for preferences are important features of person centred care<sup>3</sup>.

The previous IKCC (2018) Global Survey indicated that many patients around the world reported a lack of fundamental knowledge and understanding about their kidney cancer diagnosis. Commentary on these results stressed the critical need for healthcare providers to talk to patients and articulate the details of their diagnosis.

*“When patients have the facts and understand their options, they can be more engaged and participate more fully in their treatment. Knowledge can also help mitigate or manage psychosocial issues related to uncertainties about kidney cancer and long-term survivorship.”*

*(We need to talk about: Knowledge and understanding, 2018 IKCC Global Survey – Global Highlights Report)*

The 2020 IKCC global patient survey explored experience in this area at three key touchpoints: diagnosis; treatment planning; and overall care and treatment. This year’s survey also included a special interest in patient biopsies.

A summary of the findings from the first of the touchpoints is displayed in the box below:



### DIAGNOSIS

**3 in 4** (74% of) respondents indicated that it was less than 3 months between their first thinking that there might be something wrong to when they were correctly diagnosed.

**52%** of respondents reported not being told what subtype of kidney cancer they had when they were first correctly diagnosed.

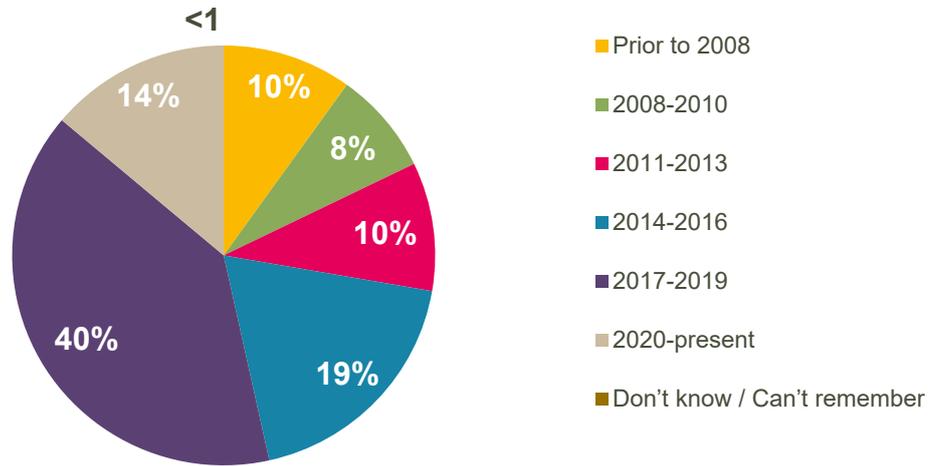
When asked about explanation at diagnosis, a large proportion of respondents said stage of kidney cancer (**18%**), subtype of kidney cancer (**34%**), treatment options (**12%**), treatment recommendations (**12%**), risk of recurrence (**31%**) and likelihood of surviving (**42%**) were not explained.

<sup>3</sup> <https://www.picker.org/about-us/picker-principles-of-person-centred-care/>

### Recency of diagnosis

Two in every five patients, carer and caregivers received a diagnosis between 2017 and 2019 (40%, n=796) – See Figure 2. In fact, just under half of all respondents reported being diagnosed before 2017 (46%, n=915).

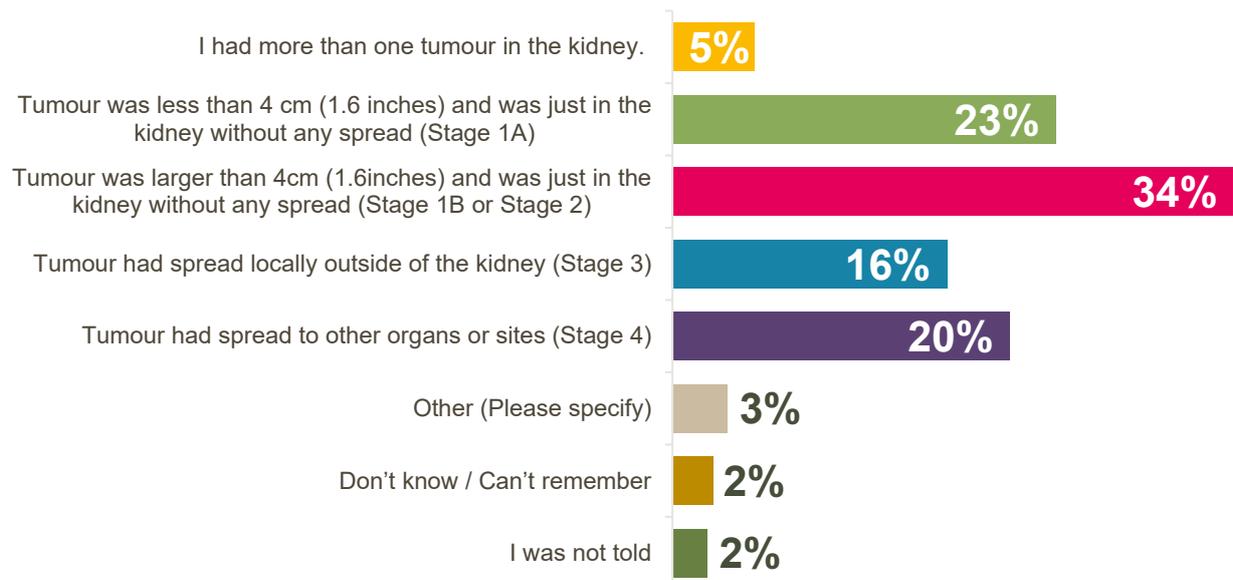
Figure 2: Q6 – In what year were you diagnosed? (n=1997)



### Stage of kidney tumour(s) at diagnosis

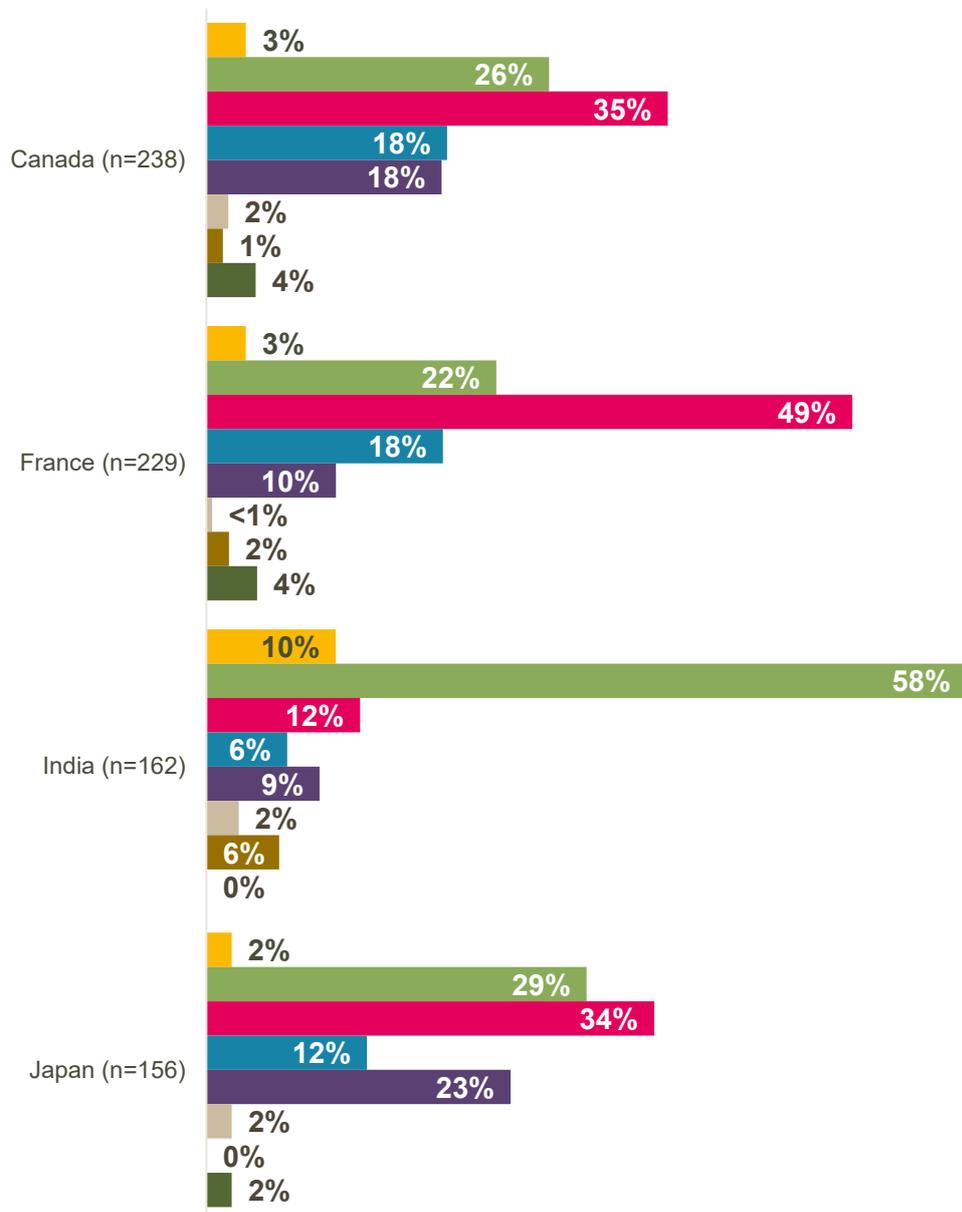
Only 2% (n=41) of total respondents indicated that they were not told the stage of their kidney tumour at the time when they first received a correct diagnosis. See Figure 3 for the complete global breakdown.

Figure 3: Q9 – At what stage was the kidney tumour when you were FIRST CORRECTLY DIAGNOSED? (Multiple choice) (n=1990)



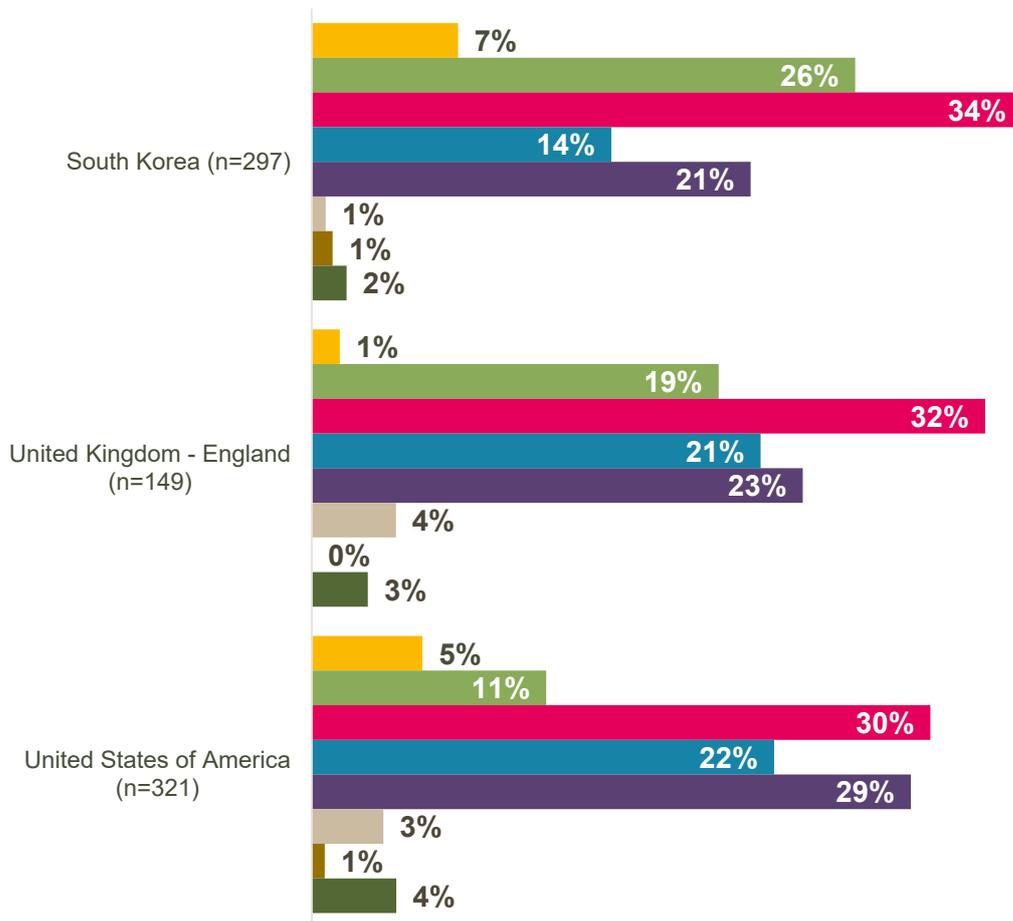
Figures 4 (i) and (ii) indicate the tumour stage at first correct diagnosis by country.

Figure 4 (i): Q9 – At what stage was the kidney tumour when you were FIRST CORRECTLY DIAGNOSED? (Multiple choice) by Country of residence (Canada, France, India and Japan)



- I had more than one tumour in the kidney.
- 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)

Figure 4 (ii): Q9 – At what stage was the kidney tumour when you were FIRST CORRECTLY DIAGNOSED? (Multiple choice) by Country of residence (South Korea, United Kingdom – England, United States of America)



- I had more than one tumour in the kidney.
- 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)

### Time to correct diagnosis

Patients were asked to consider how long it was between when they first thought something was wrong until they were correctly diagnosed. 44% (n=812) of respondents globally indicated that it took less than 1 month to receive a correct diagnosis. A further 31% (n=566) globally reported that it took between 1 and 3 months to receive a correct diagnosis. However, this varied considerably by country of residence – as shown in Figure 5.

**Figure 5: Q10+ – How long was it from the time you first thought something might be wrong with you to being CORRECTLY diagnosed? by Country of residence**

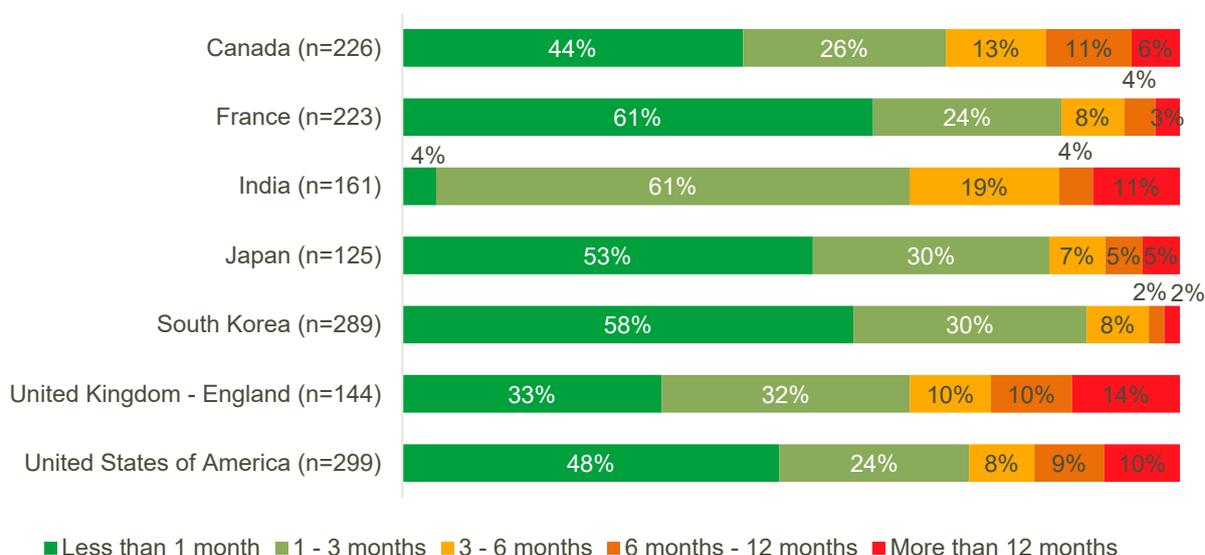


Figure 5 indicates that the greatest percentage of respondents that reported they received a correct diagnosis in under 3 months from when they first thought something was wrong were residents of South Korea (88%, n=254). However, the country with the highest percentage of respondents who reported receiving a correct diagnosis in under 1 month was France (61%, n=135) followed closely by South Korea (58%, n=167).

Only 4% (n=7) of respondents residing in India reported receiving a diagnosis in under 1 month, with a further 61% (n=98) between 1 and 3 months.

### Knowledge at time of diagnosis

There are several areas, where at diagnosis, respondents indicate that they lacked knowledge. 52% (n=909) of respondents globally reported not being told what subtype of kidney cancer they had when they were first correctly diagnosed<sup>4</sup>. The percentage of respondents that reported this varied by age demographics, as is displayed in Figure 6.

Of note, for patients diagnosed with early onset kidney cancer (under age 46), given the higher probability of hereditary syndromes and non-clear cell subtypes, with those that were under the age of 29, only 50% reported they were told their subtype, and among individuals between 30-45 years, only 53% reported they were told their subtype. These data concerning “younger onset” (n=305) patients indicate that they may not be being adequately

<sup>4</sup> It is important to recognise that this question and others about patients’ experiences of diagnosis and initial treatment were asked of everyone, no matter when they received their diagnosis – See Figure 2 for year of diagnosis. There could potentially be recall issues for those who were diagnosed a long time ago.

screened for germline mutations or being considered at higher risk for additional tumours. This is a potentially actionable unmet need.

**Figure 6: Q8+ – WHEN YOU WERE FIRST CORRECTLY DIAGNOSED, were you told what subtype of kidney cancer or kidney growth you had? - Yes by Age**



At the time of diagnosis there is a wealth of information to discuss with patients, ranging from prognosis through to treatment options. For example, a third of patients (34%, n=587) reported that kidney cancer subtype was not explained. This is a foundational piece of the diagnosis from which treatment decisions can then be made. It is important that this and other information at diagnosis is understood by patients and caregivers to facilitate their active participation in treatment decision making.

There are notable differences in reported experience between those who were diagnosed at localised and advanced stages of the disease. In general, those who were diagnosed at earlier stages generally report a more complete initial understanding of this information.

Globally at diagnosis:

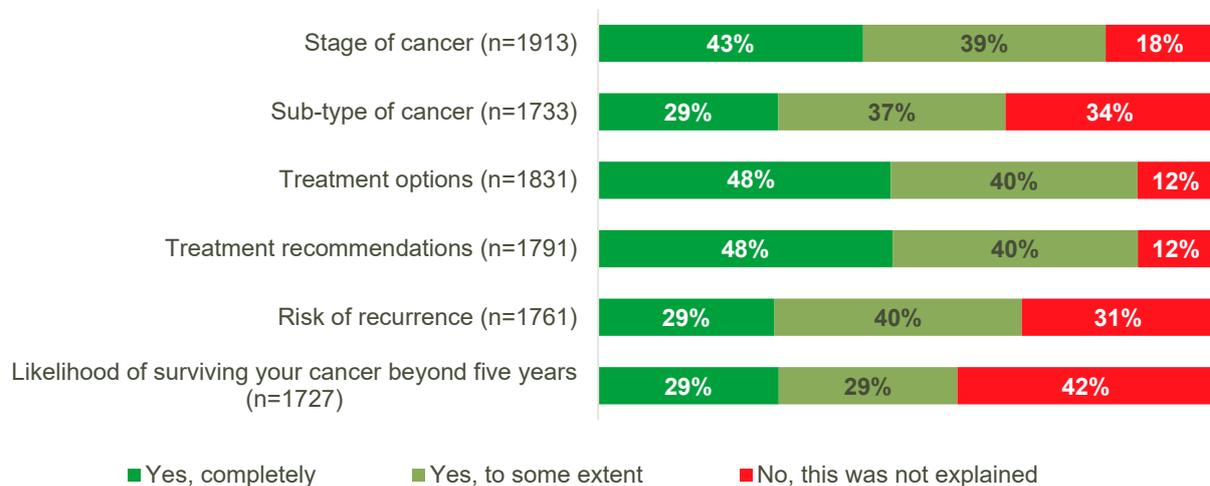
- 88% completely or to some extent understood ‘treatment options’ (n=1603)
  - This was 90% (n=896) for those with localised disease at diagnosis
  - This was 85% (n=599) for those at an advanced disease stage at diagnosis
- 88% felt that ‘treatment recommendations’ were completely/to some extent understood (n=1569)
  - Localised: 89% (n=889)
  - Advanced: 86% (n=625)
- 42% reported that the likelihood of surviving their cancer beyond five years was not explained (n=720)
  - Localised: 38% (n=363)
  - Advanced: 47% (n=305)

- 34% said that cancer subtype was not explained (n=587)
  - Localised: 35% (n=331)
  - Advanced: 32% (n=218)

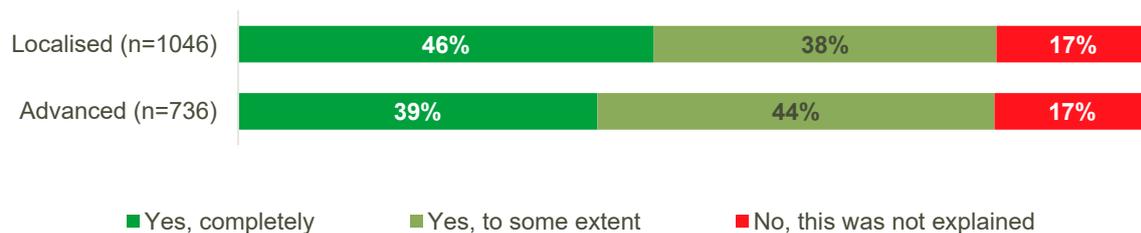
See Figure 7 for full responses to this question block (overall respondents regardless of stage), and Figures 8 to 13 for the difference in experience between those with localised and advanced disease at diagnosis.

Please note, response options “I did not need this” and “Don’t know/ can’t remember” have been suppressed in calculations – See [Derived questions](#) in Analysis and reporting for further information.

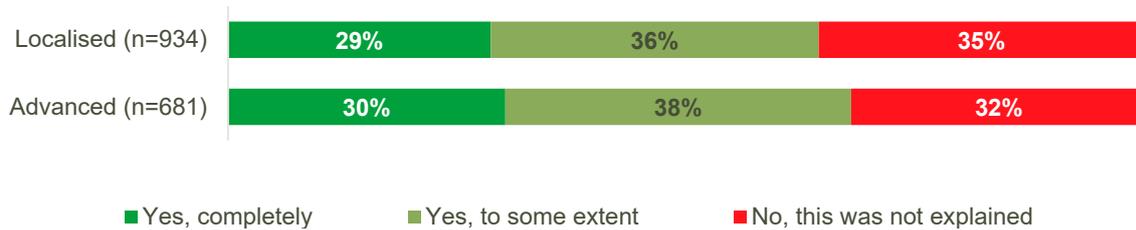
**Figure 7: Q11+ – AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand?**



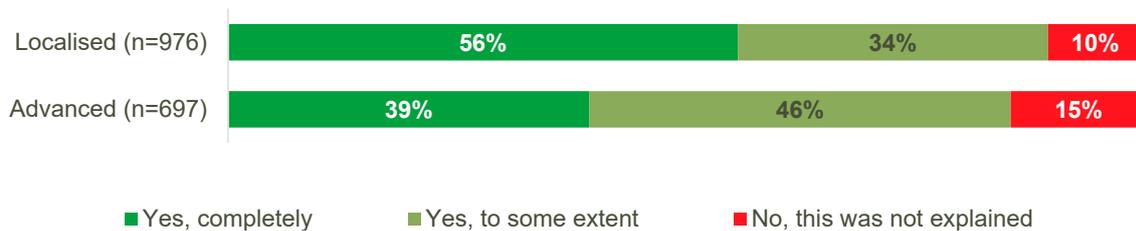
**Figure 8: Q11a+ – AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? – STAGE OF CANCER by Stage of disease at diagnosis**



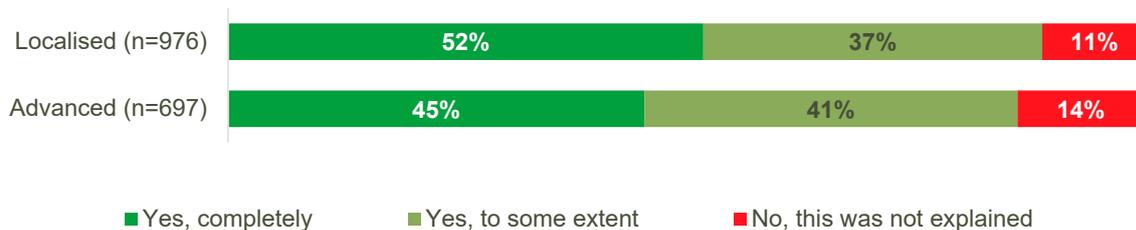
**Figure 9: Q11b+ – AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? – SUBTYPE OF CANCER by Stage of disease at diagnosis**



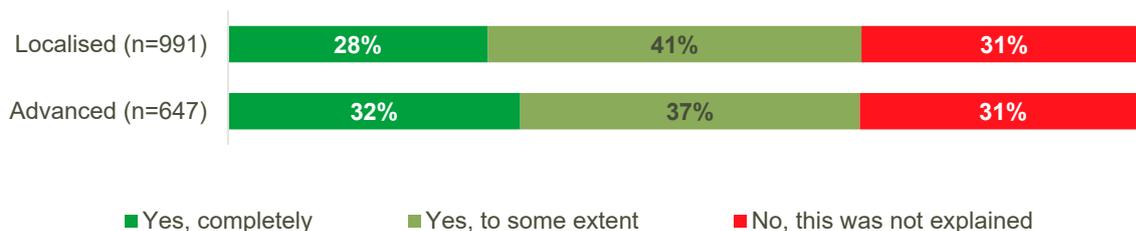
**Figure 10: Q11c+ – AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? – TREATMENT OPTIONS by Stage of disease at diagnosis**



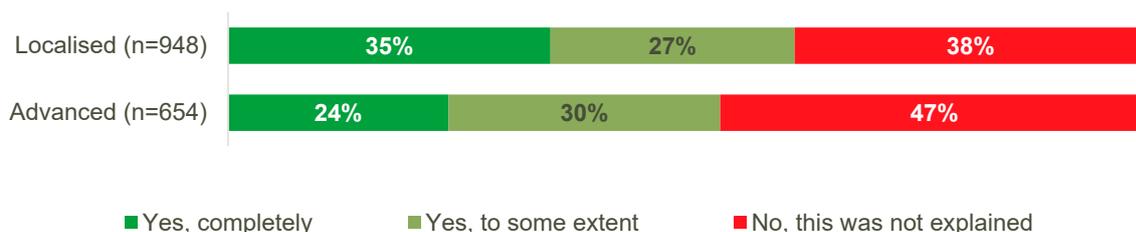
**Figure 11: Q11d+ – AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? – TREATMENT RECOMMENDATIONS by Stage of disease at diagnosis**



**Figure 12: Q11e+ – AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? – RISK OF RECURRENCE by Stage of disease at diagnosis**



**Figure 13: Q11f+ – AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? – LIKELIHOOD OF SURVIVING BEYOND 5 YEARS by Stage of disease at diagnosis**

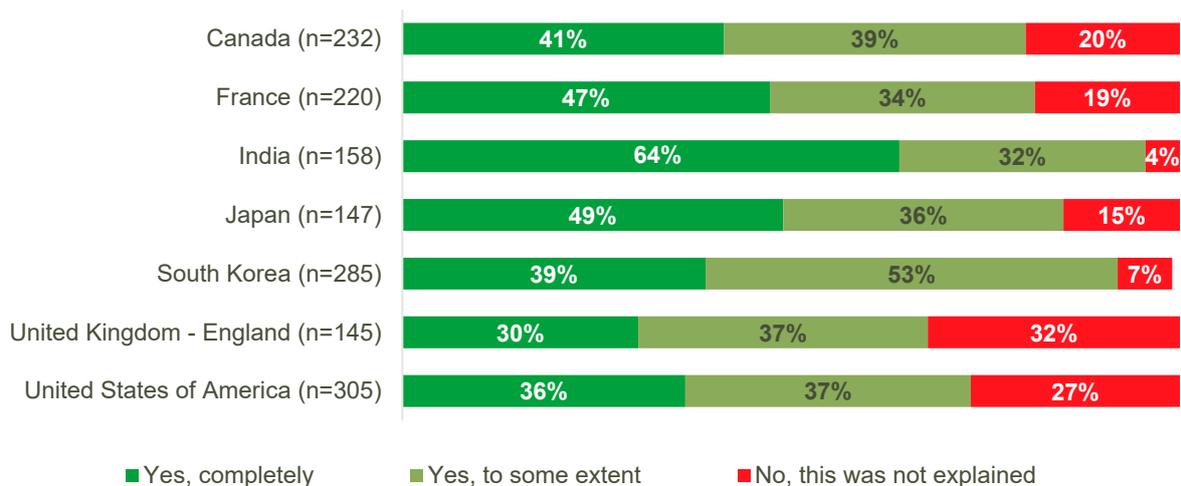


Comparing results by country revealed notable differences (see Figures 14 to 19). However, it is important to recognise the different respondent profiles for each country. In particular, the varying cancer stage at diagnosis as outlined in Figure 4 (i and ii). For more specific breakdowns, please see individual country reports.

Stage of kidney cancer at diagnosis is a vital piece of information to assist patients and caregivers in treatment decision making. In some countries (UK-England, USA), over 25% of patients did not feel that the stage had been explained in a way that they could understand – see Figure 14. This is contrasted to India (4%, n=7) and South Korea (7%, n=21) where very few patients reported lack of understanding of stage.

The greatest proportion of respondents in India 64% (n=101) reported a complete understanding about the stage of their cancer at the time of diagnosis relative to other countries displayed in Figure 14. This is striking compared to only 30% (n=44) residing in the United Kingdom – England reporting a complete understanding, with 32% (n=47) saying that stage of kidney cancer was not discussed at the time of diagnosis.

**Figure 14: Q11a+ – AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? STAGE OF CANCER by Country of residence**



When looking at only those reporting that they had a complete understanding of their cancer subtype at diagnosis, residents of France reported the most positive experience with almost half (48%, n=96) reporting that they had complete understanding – see Figure 15. The poorest response to this question was from respondents residing in the United Kingdom – England, where over half (54%, n=67) felt that their subtype was not discussed.

**Figure 15: Q11b+ – AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? SUBTYPE OF CANCER by Country of residence**

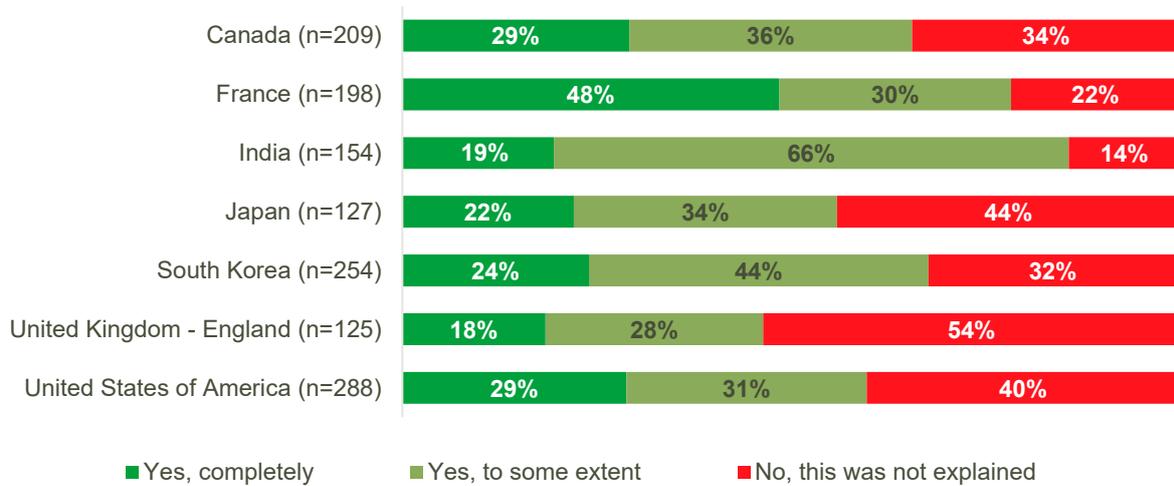
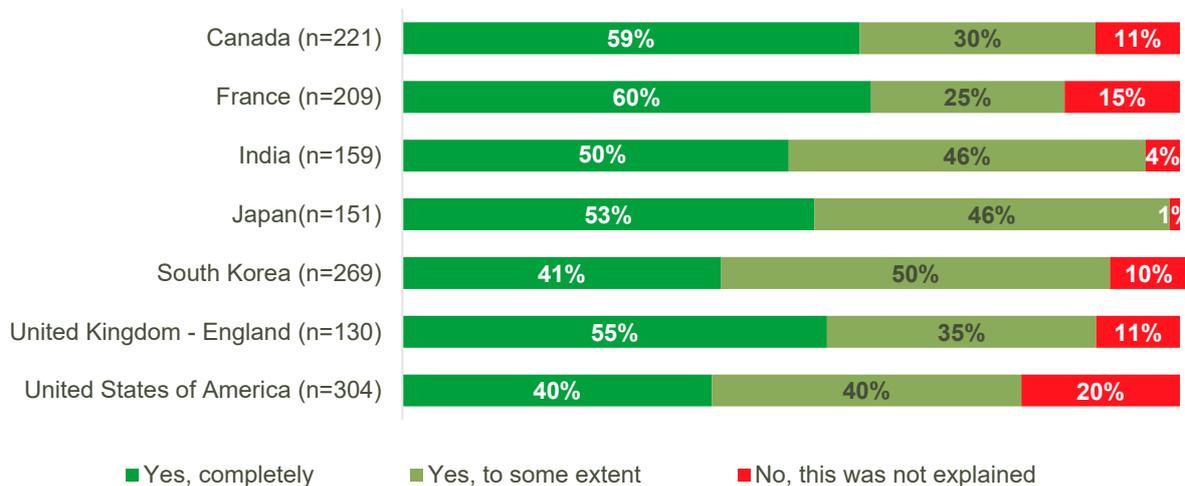


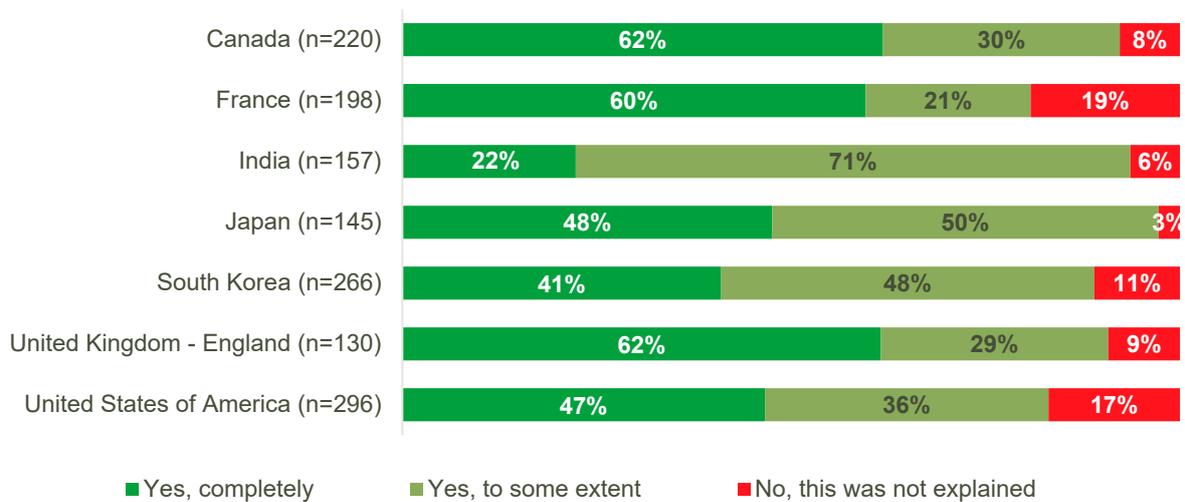
Figure 16 indicates that 99% (n=149) of residents of Japan reported that they discussed treatment options at the time of diagnosis, completely or to some extent. Whereas 1 in 5 (20%, n=62) residents of the United States suggested that treatment options were not explained.

**Figure 16: Q11c+ – AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? TREATMENT OPTIONS by Country of residence**



Residents of Japan were also the most likely to report that at the time of diagnosis they discussed treatment recommendations (completely or to some extent) – see Figure 17. Only 3% (n=4) reported that this was not explained. By comparison, 19% (n=38) of respondents in France and 17% (n=50) of those in the United States the reported the same.

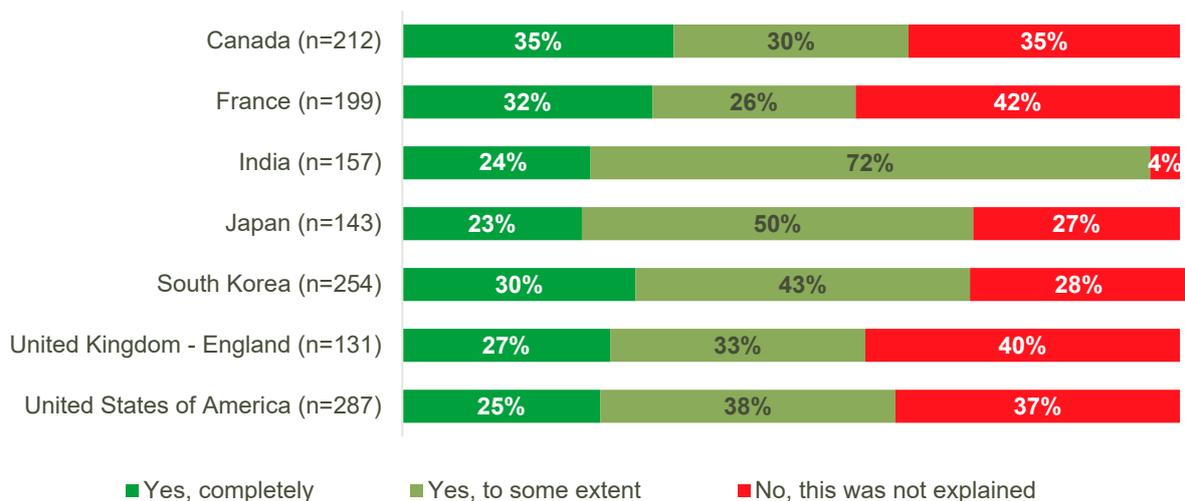
**Figure 17: Q11d+ – AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? TREATMENT RECOMMENDATIONS by Country of residence**



Risk of recurrence and likelihood of survival beyond 5 years could be considered important factors influencing psychosocial burden and long-term follow-up – see Figure 18 and Figure 19, respectively.

42% (n=83) of respondents in France and 40% (n=53) in the United Kingdom - England reported that risk of recurrence was not discussed at the time of diagnosis (Figure 18). In comparison, residents of India were more likely to report that at diagnosis, they either completely or to some extent had discussions about the risk of recurrence (96%, n=151).

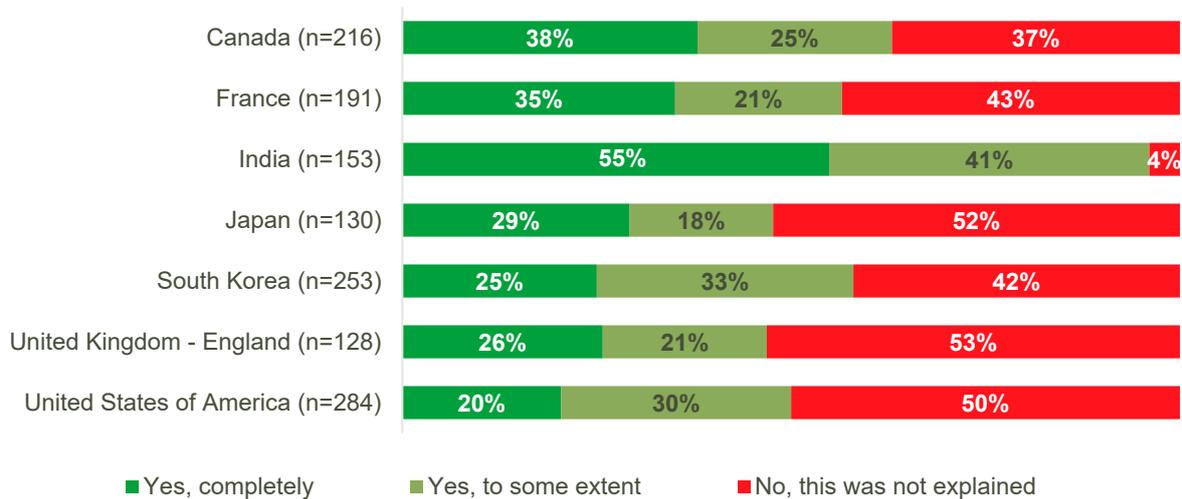
**Figure 18: Q11e+ – AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? – RISK OF RECURRENCE by Country of residence**



96% (n=147) of residents in India also indicated that they had discussed likelihood to of survival beyond 5 years at least to some extent – see Figure 19.

At least half of respondents from Japan (52%, n=68), the United Kingdom – England (53%, n=68) and United States (50%, n=142) reported that they did not discuss the likelihood of surviving beyond 5 years.

**Figure 19: Q11f+ – AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? – LIKELIHOOD OF SURVIVING BEYOND 5 YEARS by Country of residence**



### Getting a second opinion

Upon receipt of a diagnosis, only 38% (n=733) of respondents globally reported ever having received a second opinion. 51% (n=982) reported that they decided not to get a second opinion. Whereas 4% (n=75) said that this was not an option to them and 7% (n=141) indicated that they had never considered it.

Figure 20 indicates the differing experience of those with localised and advanced disease. Over half of respondents (55%, n=580), whose cancer was localised at time of diagnosis chose not to seek a second opinion from a kidney cancer expert. This can be compared to 46% (n=340) of those with advanced cancer at diagnosis.

In comparison, 36% (n=380) of respondents whose cancer was localised at diagnosis sought a second opinion as did 43% (n=318) of those in advanced stages.

**Figure 20: Q12 – Did you ever seek a second opinion with a kidney cancer expert? by Stage of disease at diagnosis**



Again, there were notable variations between countries of residence – see Figure 21.

Respondents in India and the United States were more likely to report that they had sought a second opinion relative to others. Other demographic factors may have also influenced how

people responded to this question. For example, those aged under 30 were most likely to state they never considered seeking a second opinion and that a second opinion was not available to them – See Table 2.

Figure 21: Q12 – Did you ever seek a second opinion with a kidney cancer expert? by Country of residence

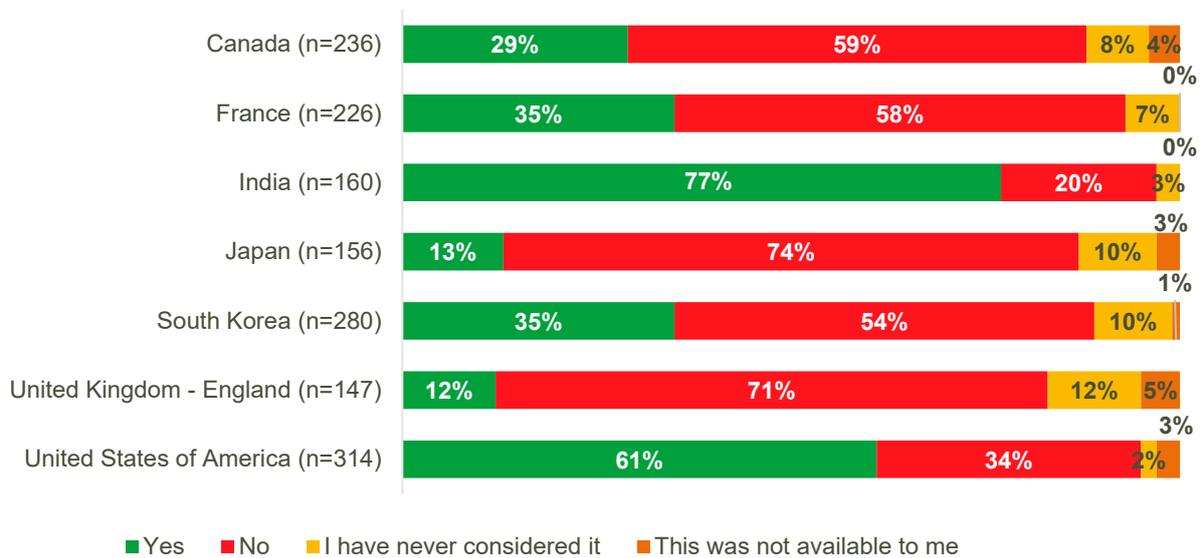


Table 2: Q12 – Did you ever seek a second opinion with a kidney cancer expert? by Age

	18-29 n=35	30-45 n=280	46-65 n=1147	66-80 n=412	80+ n=34
<b>Yes</b>	37%	35%	38%	39%	50%
<b>No</b>	34%	49%	52%	53%	42%
<b>I have never considered it</b>	14%	11%	5%	5%	9%
<b>This was not available to me</b>	14%	5%	3%	3%	0%

Figures in green indicate the most popular response option per age group

Diagnosis is only the first step in determining care and treatment. The IKCC survey also considered patient knowledge, expectation and self-reported patient-activation at the point of developing a treatment plan. Key findings are outlined in the box below.



## DEVELOPING A TREATMENT PLAN

**Approximately half** (51%) of respondents reported that they were definitely involved as much as they wanted to be in developing their treatment plan.

**56%** of respondents reported experiencing barriers to treatment.

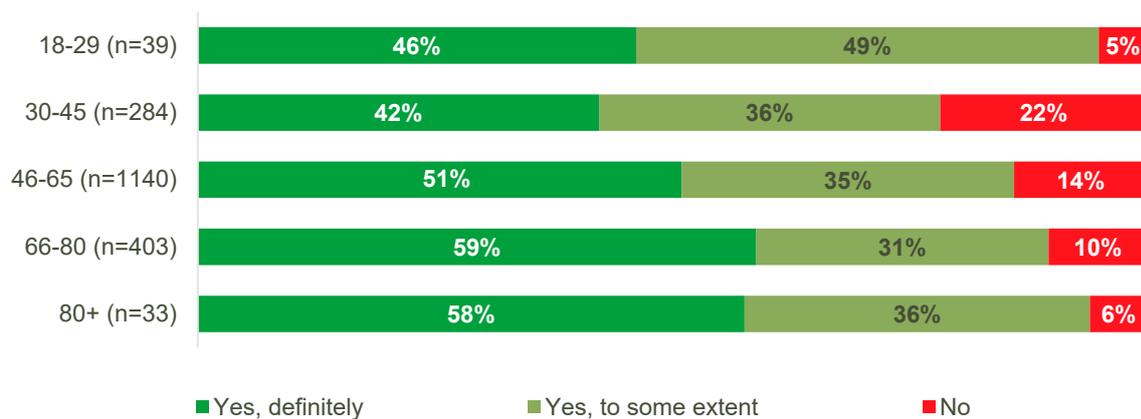
**Cost of treatment** appears to be the biggest reported barrier to treatment.

### Involvement in developing a treatment plan/shared decision making

51% (n=988) of respondents globally indicated that they were definitely involved as much as they wanted to be in decisions about their treatment plan. However, this varies by demographic group.

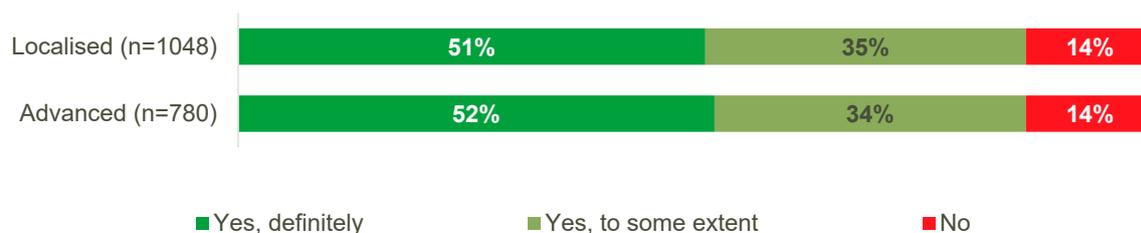
22% (n=62) of those aged between 30 and 45 reported that they were not involved as much as they wanted to be in decisions about their treatment plan – see Figure 22. This is relative to 14% or less for other age groups, (example from 46-65, n=160).

Figure 22: Q13+ – Were you involved as much as you wanted to be in decisions about your treatment plan? by Age



There was no notable difference in level of shared of decision making by stage of disease at diagnosis – see Figure 23.

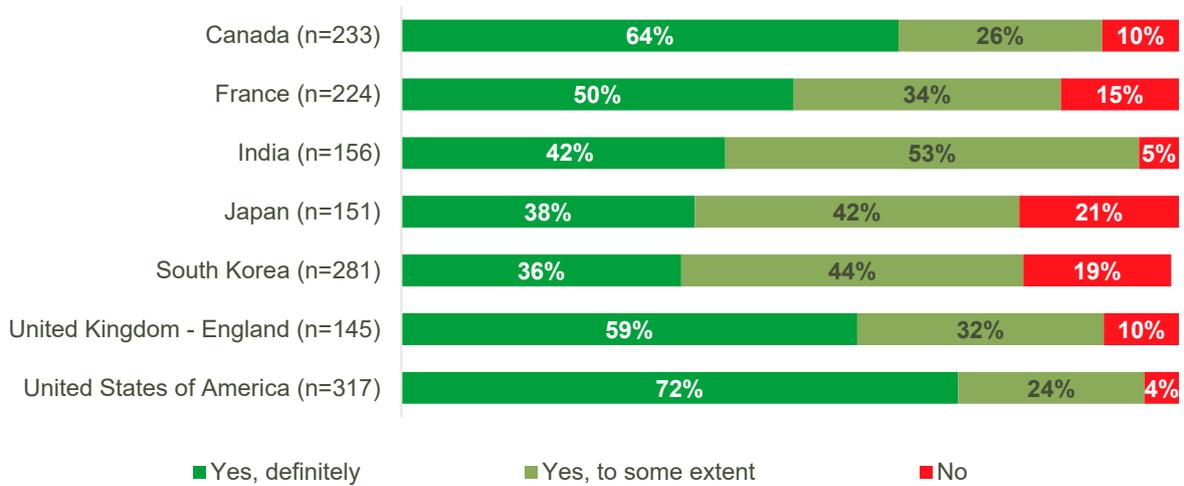
Figure 23: Q13+ – Were you involved as much as you wanted to be in decisions about your treatment plan? by Stage of disease at diagnosis



Relative to other countries, respondents in the United States reported the most favourable experience with both the greatest percentage of people reporting that they were definitely involved as much as they wanted to be in treatment plan decisions (72%, n=227), and the fewest people reporting that they were not involved as much as they would like to have been (4%, n=14) – see Figure 24.

Comparatively, respondents in South Korea and Japan reported the worst experience with both the lowest percentage of people who said that they were definitely involved as they wanted to have been (South Korea – 36%, n=102 and Japan – 38%, n=57)) and the most people reporting that they were not involved as much as they would like to have been (19%, n=54 and 21%, n=31 respectively).

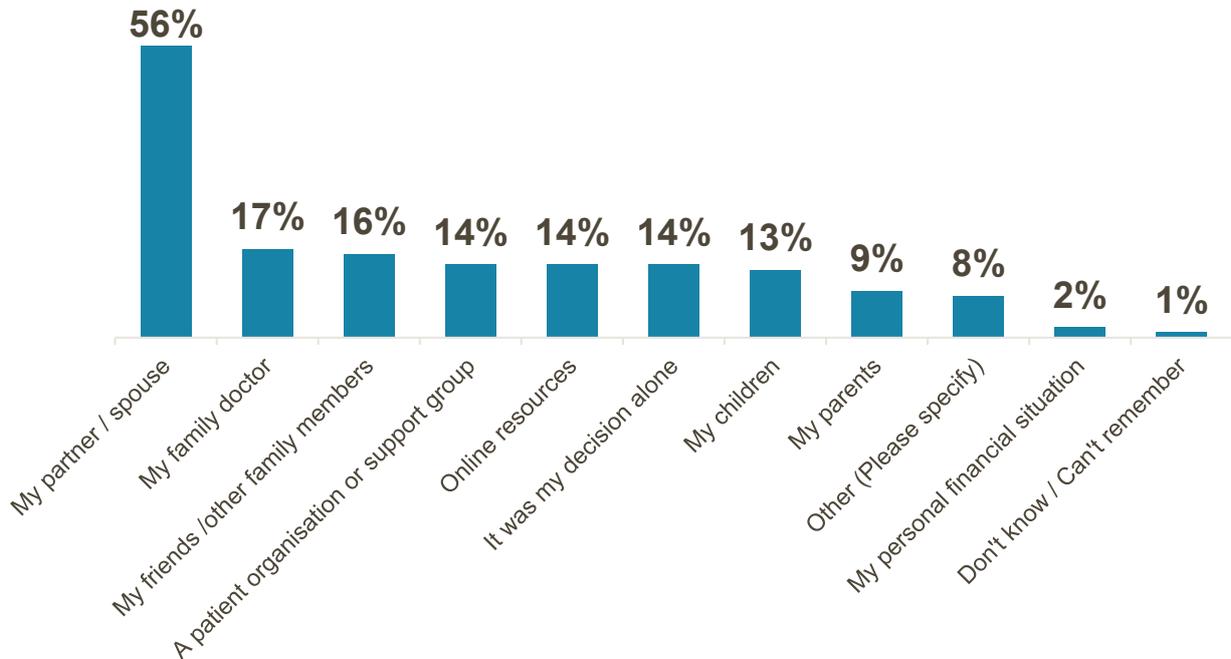
Figure 24: Q13+ – Were you involved as much as you wanted to be in decisions about your treatment plan? by Country of residence



### Sources of help with shared decision making

It is worth noting that very few respondents reported making treatment decisions alone (see Figure 25). Over half of responses (56%, n=1097) indicated that respondents involved their partner/spouse. This was notably the most common source of support when making decisions about treatment plans. Respondents also acknowledged the role of patient organisations, online resources and friends/family members.

Figure 25: Q14 – Who or what else helped you make decisions about your treatment plan? (Multiple choice) (n=1970)



## Barriers to treatment

Whilst it is positive that 44% (n=839) of total respondents reported not having any barriers to treatment, it is very important to recognise that a considerable number of patients are presented with significant barriers to receiving care. Figure 25 outlines some of these.

1,084 respondents offered 2,337 barriers that they had experienced to treatment. The percentage break of these can be seen in Figure 26.

The most commonly referenced barrier was cost of treatment (38% of respondents, n=412) and wait times (32%, n=346). 13% (n=141) of respondents noted 'other'. Text responses are available in the Freetext Data Download (see separate document).

**Figure 26: Q15+ – Which barriers (if any) have you experienced in receiving treatment for your kidney cancer or kidney growth? (Multiple choice) (n=1084)**

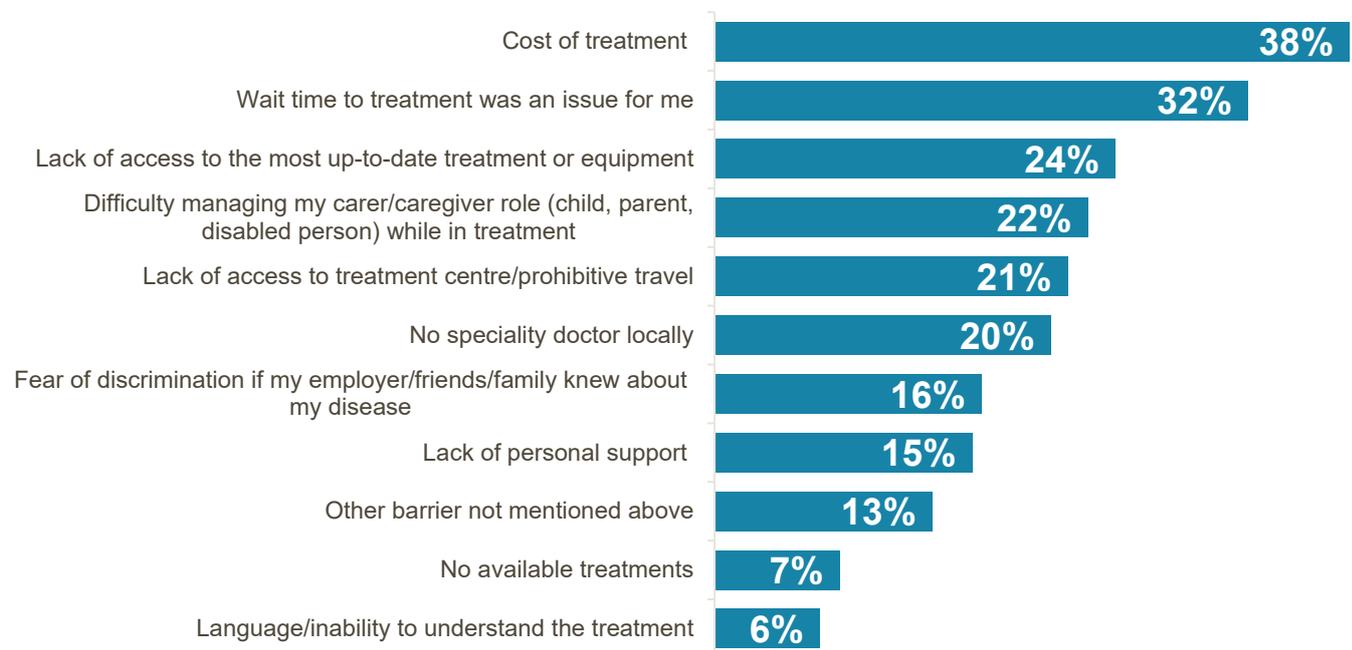


Table 3 summarises the barriers faced by respondents depending on their stage of disease at diagnosis.

Of those diagnosed in advanced stages of the disease, 43% of respondents (n=329) indicated that they experienced no barriers to treatment. A further 438 respondents noted 773 barriers that they had experienced. The five most common barriers noted were:

- Cost of treatment – a barrier reported by 35% (n=154) of respondents who experienced barriers to treatments
- No speciality doctor locally – 22% (n=95)
- Lack of access to the most up-to-date treatment or equipment – 21% (n=90)
- Wait time to treatment – 21% (n=90)
- Lack of access to treatment centre/prohibitive travel – 17% (n=73)

Comparatively, 43% (n=465) of those respondents who were diagnosed at a localised stage of the disease also reported that they experienced no barriers to treatment. However, 627 respondents indicated 1327 barriers to treatment. Two of the five most common for localised cancer stage respondents were different to those in advanced stages (see above) and were generally experienced by a greater percentage of respondents overall (bar cost of treatment):

- Wait time to treatment – 37% (n=235) of respondents who experienced barriers to treatments
- Cost of treatment – 33% (n=206)
- Difficulty managing my carer/caregiver role whilst in treatment – 26% (n=160)
- Lack of access to the most up-to-date treatment or equipment – 23% (n=144)
- Fear of discrimination if my employer/ friends/ family knew about my disease – 22% (n=141)

**Table 3: Q15+<sup>5</sup> – Which barriers (if any) have you experienced in receiving treatment for your kidney cancer or kidney growth? (Multiple choice) (n=1733) by Stage of disease at diagnosis**

	Localised	Advanced
<b>Cost of treatment</b>	<b>35%</b>	33%
<b>Lack of access to treatment centre/prohibitive travel</b>	17%	19%
<b>Language/inability to understand the treatment</b>	4%	4%
<b>Lack of access to the most up-to-date treatment or equipment</b>	21%	23%
<b>Wait time to treatment was an issue for me</b>	21%	<b>37%</b>
<b>Lack of personal support</b>	15%	13%
<b>No speciality doctor locally</b>	22%	17%
<b>Difficulty managing my carer/caregiver role whilst in treatment</b>	15%	26%
<b>Fear of discrimination if my employer/ friends/ family knew about my disease</b>	6%	22%
<b>No available treatments</b>	10%	5%
<b>Other barrier not mentioned above</b>	12%	12%
<b>Q15<sup>5</sup> – I experienced no barriers</b>	43%	43%

*Figures in red indicate most referenced barrier for the disease stage at diagnosis*

<sup>5</sup> Analysis note: Q15- "I experienced no barriers" is calculated as a percentage of the total number of respondents to answer Q15. Q15+ - All response options bar "I experienced no barriers" is a calculated as a percentage of the total number of respondents who **did** experience barriers.

Table 4 outlines these results by age category, however, take care interpreting the data due to a lower number of respondents in the youngest (18-29 years) and oldest (80+) age groups.

Notably, as age category increased, the proportion of patients that reported experiencing no barriers increased. Older patients tend to report experiencing fewer barriers to being able to receive treatment for their diagnosis.

Cost of treatment appears to be a particular barrier for those aged 18-29 (52% of respondents who experienced a barrier, n=16). It is also a concern for the largest proportion of respondents aged 30-45 (41%, n=80) and 45-65 (41%, n=1129).

**Table 4: Q15<sup>5</sup> – Which barriers (if any) have you experienced in receiving treatment for your kidney cancer or kidney growth? (Multiple choice) (n=1916) by Age**

	18-29 n=40	30-45 n=283	46-65 n=1129	66-80 n=409	80+ n=35
<b>Cost of treatment</b>	<b>52%</b>	<b>41%</b>	<b>41%</b>	24%	10%
<b>Lack of access to treatment centre/prohibitive travel</b>	32%	27%	20%	17%	10%
<b>Language/inability to understand the treatment</b>	26%	9%	5%	4%	10%
<b>Lack of access to the most up-to-date treatment or equipment</b>	29%	18%	26%	23%	10%
<b>Wait time to treatment was an issue for me</b>	19%	26%	35%	<b>30%</b>	<b>40%</b>
<b>Lack of personal support</b>	29%	14%	17%	8%	20%
<b>No speciality doctor locally</b>	13%	21%	19%	26%	30%
<b>Difficulty managing my carer/caregiver role whilst in treatment</b>	19%	22%	27%	8%	20%
<b>Fear of discrimination if my employer/friends/ family knew about my disease</b>	19%	13%	21%	3%	0%
<b>No available treatments</b>	13%	12%	5%	9%	30%
<b>Other barrier not mentioned above</b>	10%	9%	13%	18%	20%
<b>Q15<sup>5</sup> – I experienced no barriers</b>	23%	31%	42%	58%	71%

*Figures in red indicate most referenced barrier for the age category*

Exploring barriers to treatment also varied by country of residence – See Table 5.

Over 50% of respondents from three countries reported that they did not experience any barriers:

- France (76% of responses, n=169)
- Canada (59% of responses, n=138)
- United Kingdom – England (57% of responses, n=78)

In contrast, only 3 respondents in India indicated that they had experienced no barriers to treatment. The 5 most commonly reported barriers for respondents in this country were:

- Cost of treatment – 75% of respondents who experienced barriers to treatments (n=120)
- Wait time to treatment was an issue for me – 64% (n=102)
- Lack of access to the most up-to-date treatment or equipment – 58% (n=93)
- Difficulty managing my carer/caregiver role (child, parent, disabled person) while in treatment – 55% (n=88)
- Fear of discrimination if my employer/friends/family knew about my disease – 55% (n=88)

Several barriers to treatment were also articulated by residents of South Korea. Only 19% of responses (n=55) reported no barriers to care and treatment. The 3 most experienced barriers for respondents in this country were:

- Cost of treatment – 44% of respondents who experienced barriers to treatments (n=101)
- Wait time to treatment was an issue for me – 30% (n=70)
- Difficulty managing my carer/caregiver role while in treatment – 26% (n=60)

Table 5: Q15+<sup>5</sup> – Which barriers (if any) have you experienced in receiving treatment for your kidney cancer or kidney growth? (Multiple choice) (n=1302) by Country of residence

	Canada (n=232)	France (n=223)	India (n=163)	Japan (n=154)	South Korea (n=285)	UK - England (n=137)	USA (n=311)
Cost of treatment	14%	6%	<b>75%</b>	<b>46%</b>	<b>44%</b>	10%	25%
Lack of access to treatment centre/ prohibitive travel	10%	9%	41%	7%	24%	3%	18%
Language/inability to understand the treatment	3%	0%	9%	1%	4%	0%	2%
Lack of access to the most up-to-date treatment or equipment	16%	17%	58%	10%	12%	19%	12%
Wait time to treatment was an issue for me	<b>35%</b>	17%	64%	24%	30%	41%	18%
Lack of personal support	17%	15%	5%	10%	11%	<b>49%</b>	13%
No speciality doctor locally	22%	19%	14%	11%	20%	17%	<b>34%</b>
Difficulty managing my carer/caregiver role while in treatment	10%	9%	55%	21%	26%	17%	12%
Fear of discrimination if my employer/ friends/ family knew about my disease	6%	4%	55%	18%	10%	8%	12%
No available treatments	7%	4%	1%	3%	10%	0%	8%
Other barrier not mentioned above	24%	<b>33%</b>	0%	10%	3%	19%	26%
<b>Q15<sup>5</sup> – I experienced no barriers</b>	<b>59%</b>	<b>76%</b>	<b>2%</b>	<b>32%</b>	<b>19%</b>	<b>57%</b>	<b>61%</b>

Figures in red indicate most referenced barrier for the country category

The 2020 IKCC global patient survey also considered, people’s experience of care today.

A summary of the findings is displayed in the box below:



## CARE & TREATMENT TODAY

**30%** of respondents had a biopsy of the kidney growth, and a further **15%** of respondents had a biopsy of another part of their body.

**3%** of respondents were offered a biopsy but chose not to have one.

**47%** of respondents would be willing to have a biopsy in future if necessary, whilst **39%** said they would maybe agree to a biopsy in future.

Levels of understanding of treatment options ranged from **90%** of respondents understanding surgical options to **56%** understanding ablative therapy options.

### Stage of kidney tumour(s) today

Figure 27 indicates a shift in respondents' stage of kidney cancer/ growth today in comparison to the stage of the growth at first diagnosis (shown in Figure 3). Over one third of respondents (36%, n=690) have indicated that their kidney cancer/growth has spread to other organs or distant sites (stage 4).

**Figure 27: Q16 – Which of the following best describes your stage of kidney cancer or kidney growth TODAY? (n=1913)**

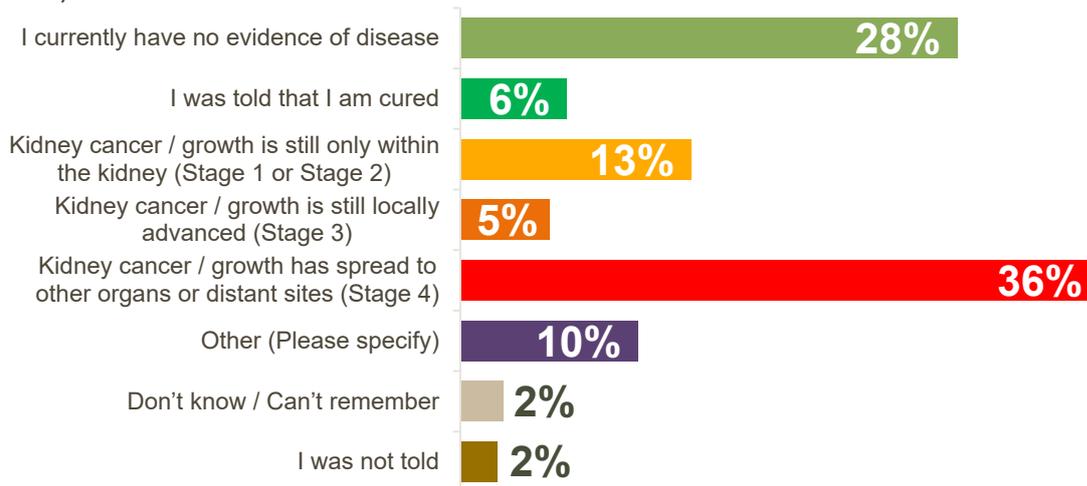
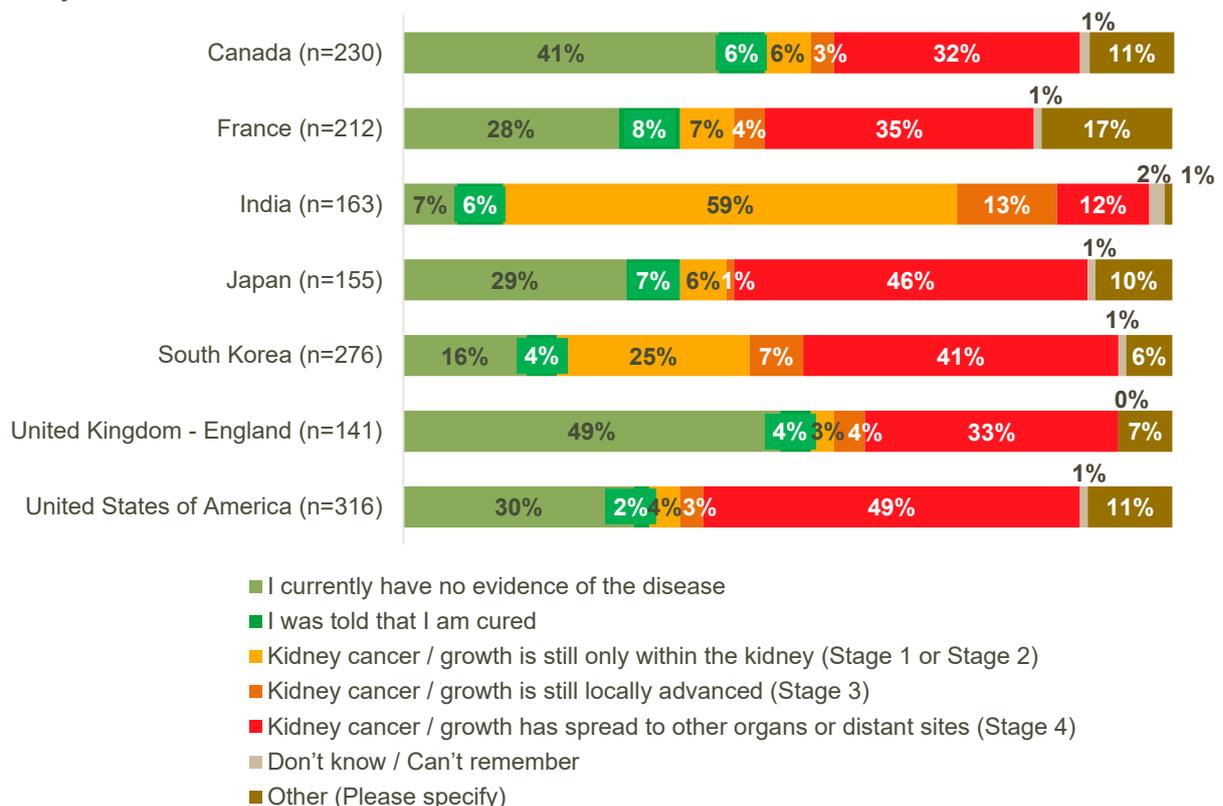


Figure 28 indicates the current stage varies by country.

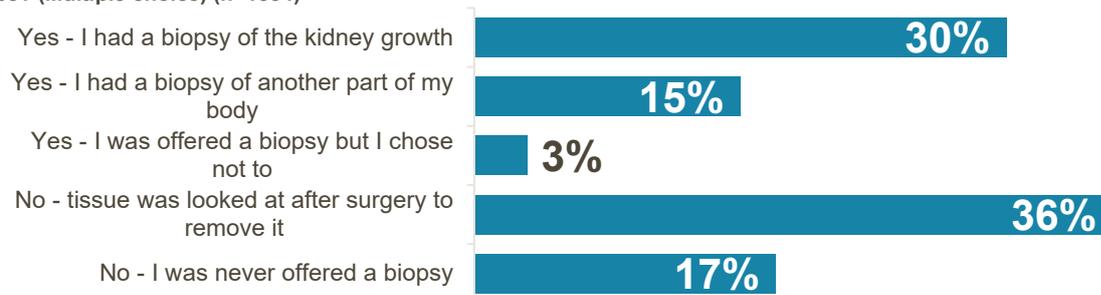
**Figure 28: Q16 – Which of the following best describes your stage of kidney cancer or kidney growth TODAY? by Country of residence**



### Biopsy practice

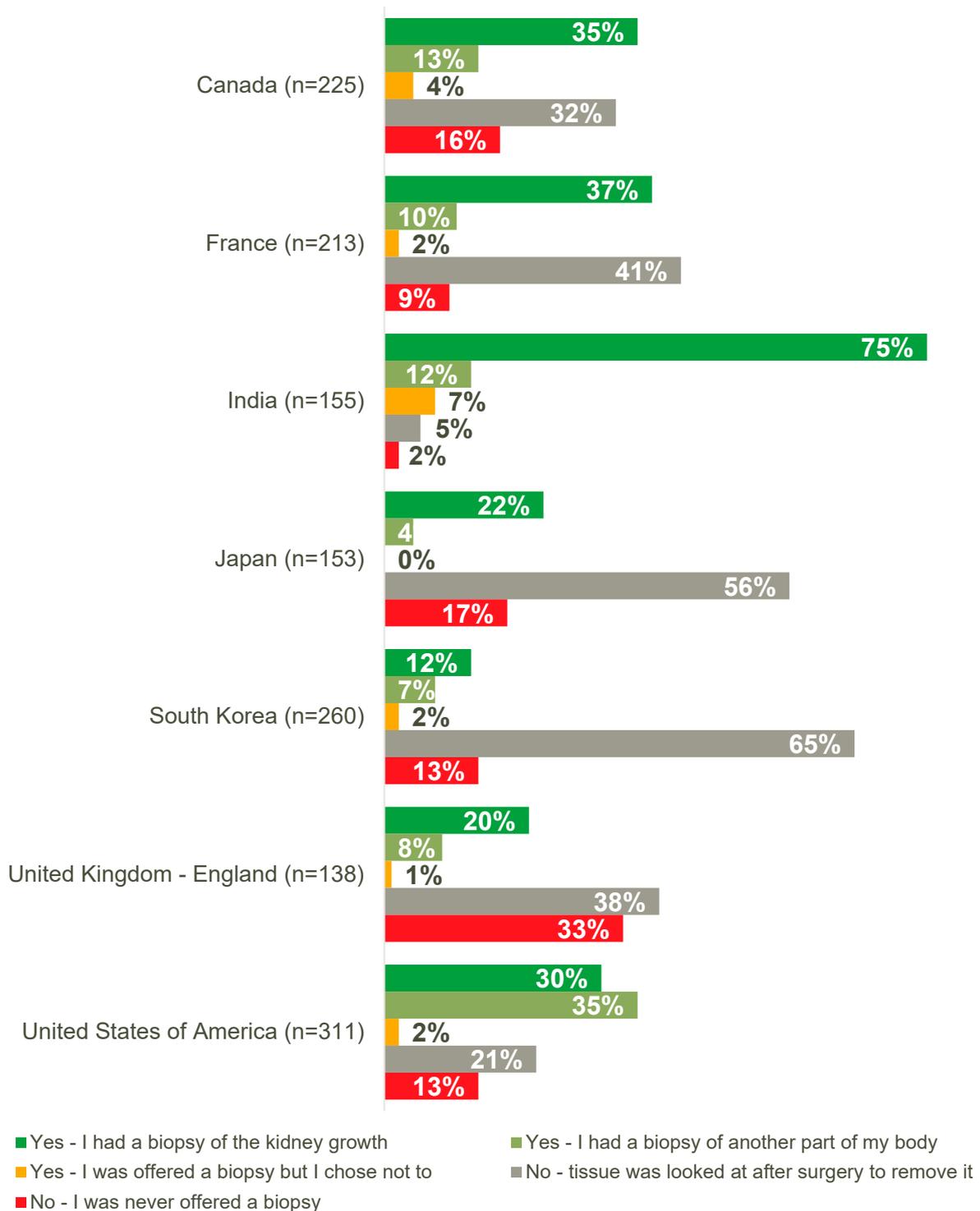
Overall, 45% (n=829) of respondents had a biopsy either on a kidney growth or another part of the body – See Figure 29. A further 36% (n=664) reported that their tissue was examined after surgery to remove it. Only 3% (n= 47) of respondents indicated that they had been offered a biopsy but chose not to proceed with it.

**Figure 29: Q19 – Have you ever been offered a biopsy of some part of your body where kidney cancer was thought to be? (Multiple choice) (n=1854)**



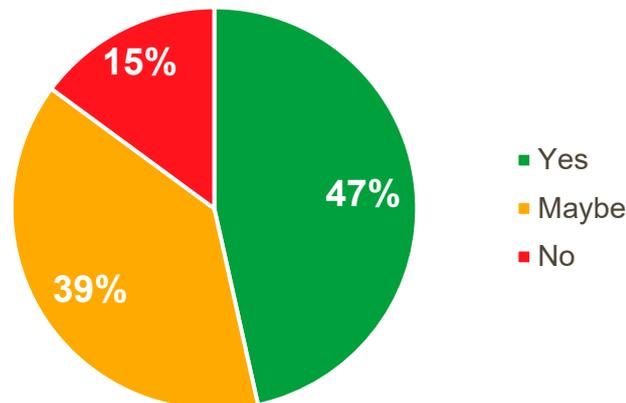
There are notable differences depending on the respondents' country of residence. These are outlined in Figure 30.

Figure 30: Q19 – Have you ever been offered a biopsy of some part of your body where kidney cancer was thought to be? (Multiple choice) by Country of residence



As outlined in Figure 31, 47% (n=474) of respondents indicated that they would be willing to have a biopsy again in the future, if necessary and only 15% (n=151) indicated that they would not.

Figure 31: Q20 – Would you be willing to have a biopsy in the future if necessary? (n=1018)



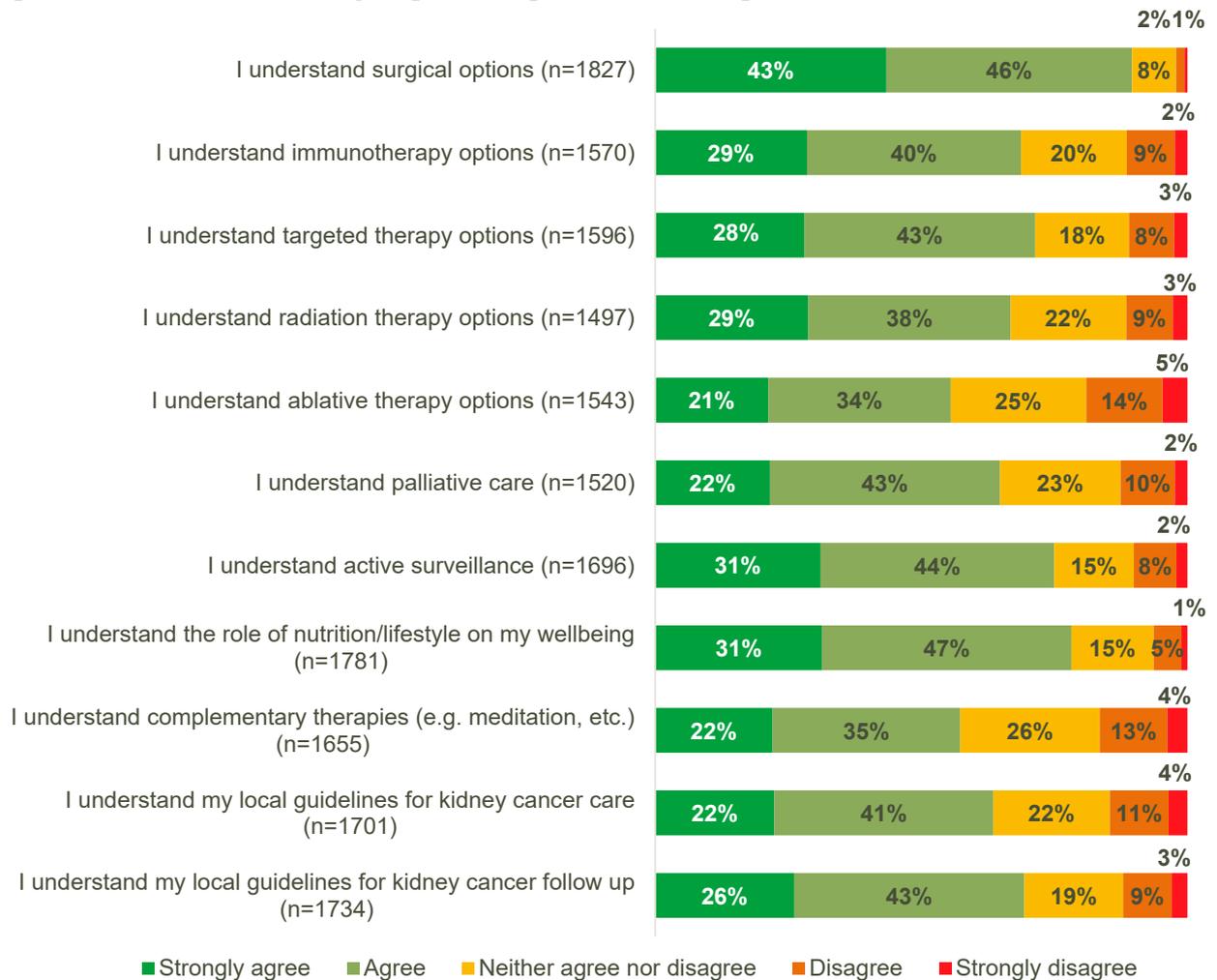
### Understanding of care and treatment

Respondents had varying levels of understanding regarding care options and treatment – see Figure 32. The 2020 International Kidney Cancer Coalition Global Survey asked respondents about their understanding of:

- surgical options
- immunotherapy options
- targeted therapy options
- radiation therapy options
- ablative therapy options
- palliative care
- active surveillance
- the role of nutrition/lifestyle on my wellbeing
- complementary therapies (e.g. meditation, etc.)
- local guidelines for kidney cancer care
- local guidelines for kidney cancer follow up

Globally, the lowest reported levels of understanding related to ablative care, where 56% (n= 857) of global respondents agreed or strongly agreed that they understood options. Similarly, globally only 57% (n=949) of respondents reported understanding of any complementary therapy such as meditation. This may be an actionable finding with regard to addressing psychosocial burden including anxiety and distress.

Figure 32: Q18+ – To what extent do you agree or disagree with the following statements?



It is also important to consider current levels of understanding relative to respondents' stage of kidney cancer today, as outlined in Table 6.

Overall, those whose cancer was at an advanced stage at time of responding, indicated that they had on average a better understanding of their care and treatment. However, there was no great difference between the reported experience of those whose cancer was localised or who showed no evidence of the disease/had been informed that they were cured.

**Table 6: Q18+ – To what extent do you agree or disagree with the following statements? – Strongly agree/Agree by Stage of cancer today**

	Localised (n=250)	Advanced (n=787)	No evidence of disease / cured (n=649)
I understand surgical options	91%	86%	95%
I understand immunotherapy options	38%	84%	56%
I understand targeted therapy options	55%	83%	58%
I understand radiation therapy options	76%	70%	55%
I understand ablative therapy options	56%	56%	53%
I understand palliative care	41%	69%	67%
I understand active surveillance	61%	75%	79%
I understand the role of nutrition/lifestyle on my wellbeing	86%	76%	78%
I understand complementary therapies (e.g. meditation, etc.)	71%	53%	56%
I understand my local guidelines for kidney cancer care	78%	60%	61%
I understand my local guidelines for kidney cancer follow up	81%	66%	70%
<b>Average</b>	<b>67%</b>	<b>71%</b>	<b>66%</b>

When feedback to these questions is considered by country of residence, there are striking differences that may provide commentary on where certain protocols may be readily available. Differences are outlined in Table 7.

Respondents in France report some of the best understanding of treatment options. Whereas respondents in India report some of the best understanding of local guidelines.

For many of the statements there is a wide range of reported understanding when considering the results at country level. In particular, the notable range regarding understanding of:

- Complementary therapies – Range 71%, from 21% (n=24) of respondents in Japan to 92% (n=146) in India
- Active surveillance – Range 70%, from 22% (n=26) in Japan to 92% (n=166) in France
- Local guidelines for kidney cancer follow up – Range 64%, from 32% (n=43) in Japan to 96% (n=152) in India

It is also worth noting, the areas where there is unusually low reported understanding:

- 37% reported understanding of immunotherapy options in India (n=59)
- 45% reported understanding of radiation therapy options in the United Kingdom – England (n=49)

- 31% reported understanding of ablative therapy options in the United Kingdom – England (n=32)
- 43% reported understanding of palliative options in India (n=68)
- 22% reported understanding of active surveillance in Japan (n=26)
- 36% reported understanding of local guidelines for care in the United Kingdom – England (n=48)
- 32% reported understanding of local guidelines for follow-up in Japan (n=43)

However, it is important to note that the statement terms have been developed in English with a European background and some terminology may not be as extensively used outside of this setting. There might be cultural and language influences on how people in different countries have responded to the above questions.

**Table 7: Q18+ – To what extent do you agree or disagree with the following statements? – Strongly agree/Agree by Country of residence**

	Canada (n=239)	France (n=234)	India (n=162)	Japan (n=156)	South Korea (n=300)	UK - England (n=149)	USA (n=321)
I understand surgical options	90%	<b>95%</b>	94%	95%	<b>84%</b>	90%	90%
I understand immunotherapy options	59%	<b>89%</b>	<b>37%</b>	72%	73%	67%	76%
I understand targeted therapy options	62%	<b>89%</b>	<b>60%</b>	78%	77%	64%	73%
I understand radiation therapy options	63%	84%	<b>94%</b>	60%	64%	<b>45%</b>	64%
I understand ablative therapy options	44%	83%	59%	<b>86%</b>	55%	<b>31%</b>	48%
I understand palliative care	64%	<b>74%</b>	<b>43%</b>	60%	62%	74%	64%
I understand active surveillance	83%	<b>92%</b>	52%	<b>22%</b>	73%	77%	88%
I understand the role of nutrition/lifestyle on my wellbeing	79%	79%	<b>96%</b>	<b>62%</b>	81%	67%	78%
I understand complementary therapies (e.g. meditation, etc.)	52%	60%	<b>92%</b>	<b>21%</b>	52%	49%	57%
I understand my local guidelines for kidney cancer care	59%	68%	<b>94%</b>	44%	66%	<b>36%</b>	63%
I understand my local guidelines for kidney cancer follow up	70%	79%	<b>96%</b>	<b>32%</b>	65%	49%	73%
<b>Average</b>	66%	81%	74%	57%	68%	59%	70%

*Figures in green indicate the country with the reported best understanding  
Figures in red indicate the country with the reported worst understanding*

## Clinical trials, research awareness and sources of information

Effective treatment by trusted professionals is a key element of person centred care<sup>6</sup>, this is driven by research and progress.

The IKCC recognises clinical trials as the cornerstone for advancing treatment in kidney cancer. However, the IKCC (2018) Global Survey suggested that only a third of patients were asked to take part in a clinical trial. Most who were invited to take part, did and were satisfied with their experience.

*“We need to talk about clinical trials – not only when we think a patient may potentially enroll in a specific study, but more broadly whenever there is an opportunity for them to help move our understanding of kidney cancer forward.”*

*(We need to talk about: Knowledge and understanding, 2018 IKCC Global Survey – Global Highlights Report)*

The 2020 IKCC global patient survey explored awareness of cancer clinical trials and the experience of those who participated.

A summary of the findings from these sections is displayed in the box below:



### AWARENESS & EXPERIENCE

**46%** of respondents indicated that “No one” discussed cancer clinical trials with them, whether that be a doctor/nurse, spouse/friend/family, patient organisation/support group or other.

**Under a third** (31%) of respondents were invited to take part in a clinical trial.

**62%** of respondents that had the opportunity to participate in a cancer clinical trial reported that they did. **67%** of these were satisfied with their experience overall and **8%** were dissatisfied.

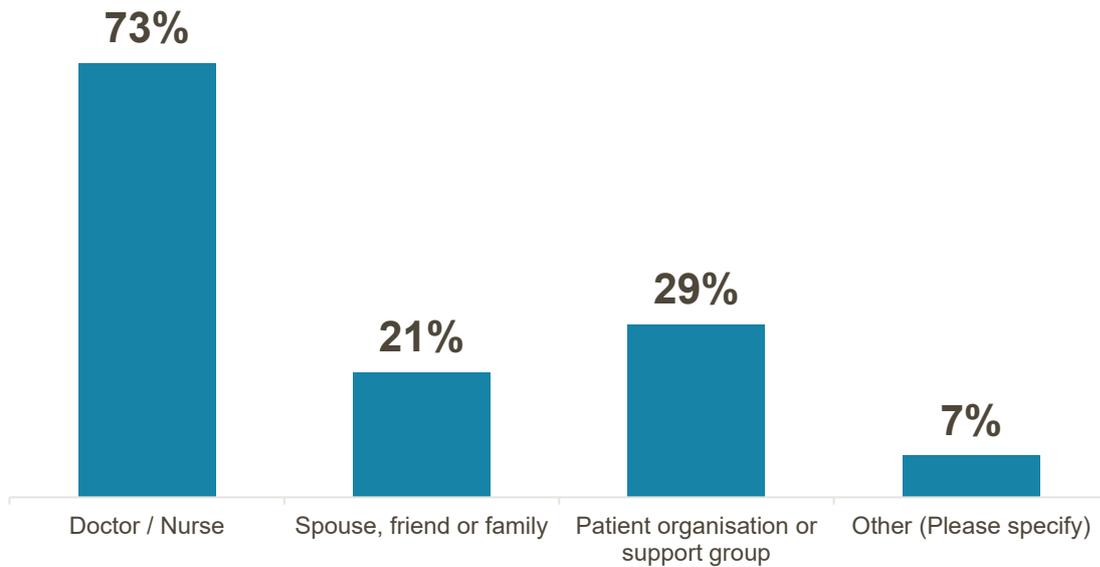
<sup>6</sup> <https://www.picker.org/about-us/picker-principles-of-person-centred-care/>

### Awareness of clinical trials

46% (n=855) of respondents reported that no one had discussed clinical trials with them.

Figure 33 outlines the groups of people that respondents indicated spoke to them about cancer clinical trials. 73% (n=697) of the responses that indicated that somebody had spoken to them about clinical trials noted that either a doctor or a nurse had discussed the topic. Almost a third (29%, n=280) of responses indicated that clinical trials had been discussed by a patient organisation or support group.

Figure 33: Q26+ – Who, if anyone, has discussed cancer clinical trials with you? (Multiple choice) (n=1244)

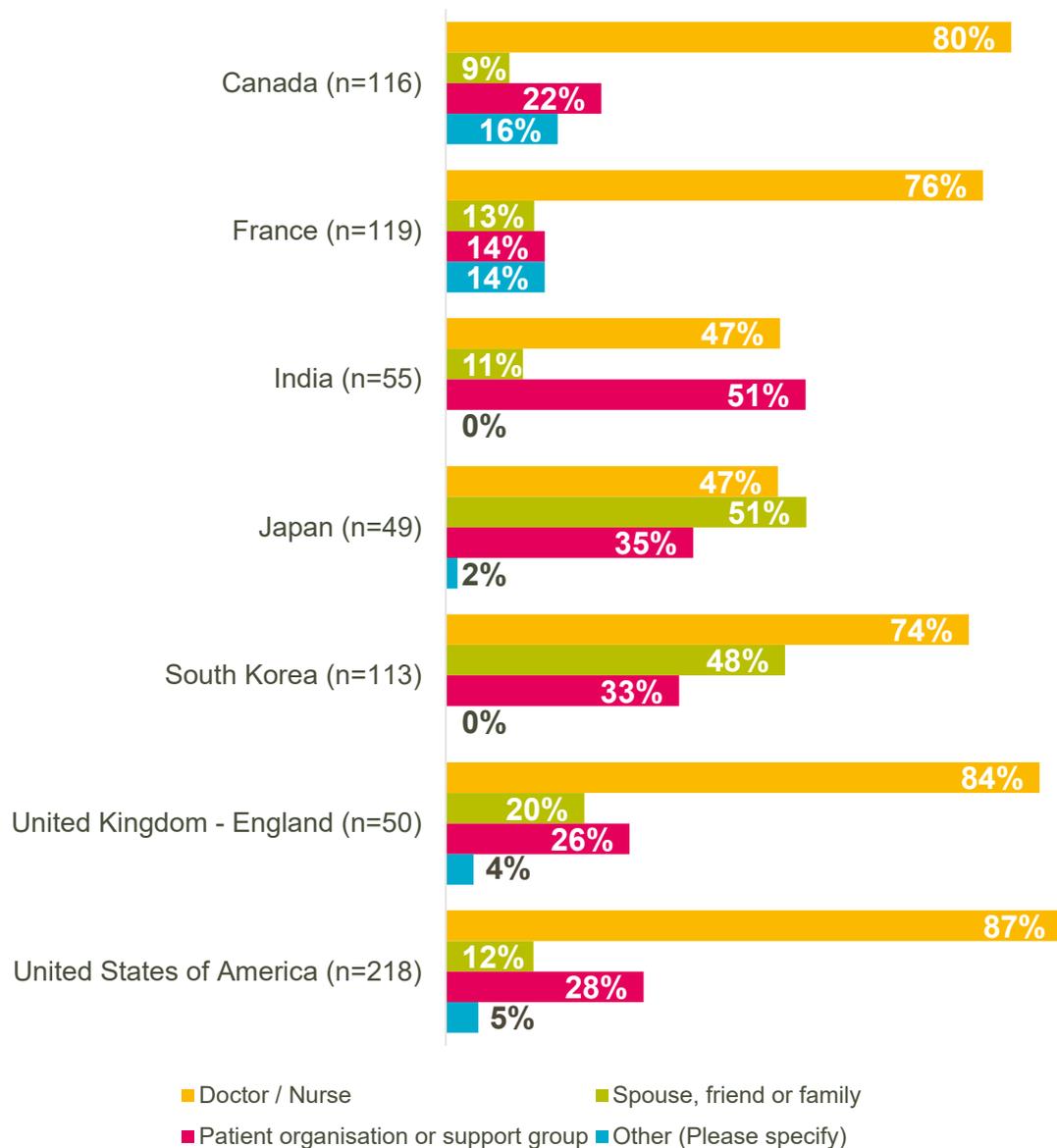


Once again, there was variation between geographies. The United States had notably fewer respondents indicating that no one spoke to them about cancer clinical trials (30%, n=93) compared to 66% (n=108) of respondents who resided in India. Other countries where more than half of respondents indicated that no one spoke to them about cancer clinical trials are Japan (58%, n=83) and the United Kingdom (62%, n=84).

Where respondents did report that someone had discussed cancer clinical trials with them (see Figure 34 for a breakdown by country), the majority of responses usually included reference to a discussion with a doctor/nurse. This was not the case for Japan and India however, where doctor/nurse accounted for less than half of the responses. For residents of Japan, the most referenced source for discussion was “Spouse, friend or family” (51% of responses, n=25). For residents of India it was “Patient organisation or support group” (51% of responses, n=28).

Note that, second only to ‘Doctor/Nurse’, a patient organisation or support group was noted to be a source of information about kidney cancer clinical trials to 29% of responses (n=280). These data likely reflect the bias of this survey, which was promoted by IKCC Affiliate patient organisations.

Figure 34: Q26+ – Who, if anyone, has discussed cancer clinical trials with you? (Multiple choice) by Country of residence



When asked participants were asked whether they would be likely to agree to participate in a clinical trial in the future, 65% (n=848) indicated that they would be likely or very likely to participate if asked.

### Taking part in clinical trials

Overall, under a third (31%, n=549) of respondents indicated that they were invited to take part in a clinical trial. This ranged from 15% (n=22) of patients based in Japan to 42% (n=132) of patients in the United States.

Of those that were invited to take part in a clinical trial, 62% (n=529) agreed to take part, this ranged from 43% in India (n=18) to 70% in South Korea (n=76). It is well worth considering

the reasons respondents gave as to why they decided to take part. These are outlined in Table 8.

Overall, the most popular reasons given for deciding to take part were that:

- A patient’s doctor had recommended it
- They thought it might offer better care
- They wanted a chance to support cancer research

**Table 8: Q29 – Why did you agree to participate? (Multiple choice) by Country of residence (Please note, feedback has been suppressed where respondent numbers are below 30)**

	Canada (n=68)	France (n=70)	South Korea (n=76)	UK - England (n=32)	USA (n=111)
<b>My doctor recommended it</b>	68%	54%	64%	53%	66%
<b>I thought it might offer better care</b>	59%	47%	70%	69%	52%
<b>I wanted a specific type of treatment</b>	16%	13%	7%	13%	21%
<b>It was my only option for treatment</b>	24%	16%	14%	6%	12%
<b>I wanted to help kidney cancer research</b>	50%	57%	8%	69%	52%
<b>Affordability, financial reasons</b>	3%	1%	34%	0%	14%
<b>Don't know / Can't remember</b>	0%	0%	0%	0%	0%
<b>Other</b>	9%	4%	4%	13%	14%

The majority of respondents who reported taking part in cancer clinical trials indicated that they were satisfied / very satisfied with their overall experience (67%, n=338) with 37% (n=185) overall indicating that they were very satisfied. 8% (n=40) indicated that they were dissatisfied/ very dissatisfied with their overall experience of their cancer clinical trial. The remaining 25% (n=125) indicated that they were neither satisfied nor dissatisfied.

## Quality of life and overall health status of respondents

Person-centred care recognises the impact that healthcare has on an individual's quality of life and in turn how an individual's quality of life and engagement with survivorship can have on overall health outcomes.

The previous IKCC (2018) Global Survey indicated that many patients choose to 'suffer in silence' regarding the physical and psychological effects of their disease.

*“We need to break the silence and start talking about the physical and psychological effects of kidney cancer.”*

*(We need to talk about: Knowledge and understanding, 2018 IKCC Global Survey – Global Highlights Report)*

The 2020 IKCC global patient survey explored:

- Current levels of physical activity: assessing to what extent patients undertake physical activity as part of their overall survivorship.
- Psycho-social wellbeing: focusing on overall emotional well-being since diagnosis.
- Patient health engagement: this is considered a key factor to improving healthcare delivery and the 2020 IKCC global patient survey utilised the Patient Health Engagement scale (PHE-S) as a “scientific measure of the psychological experience of patients’ engagement in their own care” (Graffigna and Barelo, 2018<sup>7</sup>) based on the “Patient Health Engagement” (PHE) model involving four developmental phases, namely, “blackout”, “arousal”, “adhesion” and “eudaimonic project” (purpose and meaning)

As a reminder, this survey ran during the global coronavirus pandemic and responses may have been influenced by people's experiences during those unprecedented times.

A summary of the findings from the first of these is displayed in the box below:

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<sup>7</sup> Graffigna, G., & Barelo, S. (2018). Spotlight on the Patient Health Engagement model (PHE model): a psychosocial theory to understand people's meaningful engagement in their own health care. *Patient preference and adherence*, 12, 1261–1271. <https://doi.org/10.2147/PPA.S145646>.



## HEALTH STATUS

**Half** (50%) of respondents indicated that they 'very often' or 'always' experienced disease-related anxiety.

**55%** of respondents indicated that they 'very often' or 'always' experienced a fear of recurrence.

The vast majority of respondents have indicated a physical or emotional concern, yet only **52%** of respondents reported having talked to their doctor / healthcare professional about their concerns.

### Physical activity

Physical activity is a safe and helpful way for individuals living with and beyond cancer to lessen the impact of cancer treatment on their physical and mental health, including kidney cancer survivors. Cancer survivors should be moving throughout their cancer therapy and survivorship as much as tolerated.

Experts now recommend that cancer patients and survivors perform aerobic and resistance training for approximately 30 minutes per session, three times a week, to achieve these health benefits. Even some physical activity is better than none.

A new question has been added asking about current levels of physical activity to assess to what extent patients undertake physical activity as part of their overall survivorship.

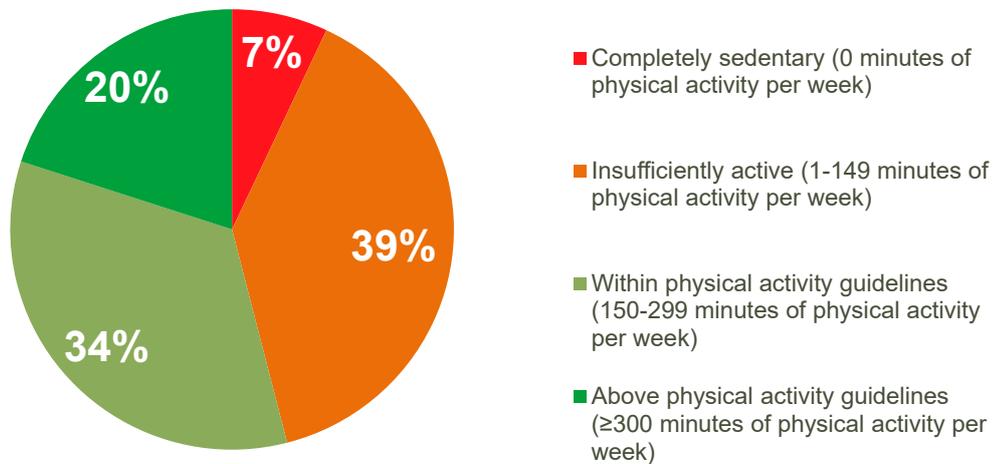
### Current levels of physical activity

46%<sup>8</sup> of respondents (n=830) self-reported that they were insufficiently active or completely sedentary. At the other end of the spectrum, 1 in 5 (20%, n=352) replied that they exercised above the physical activity guidelines ( $\geq 300$  minutes of physical activity per week) – see Figure 35.

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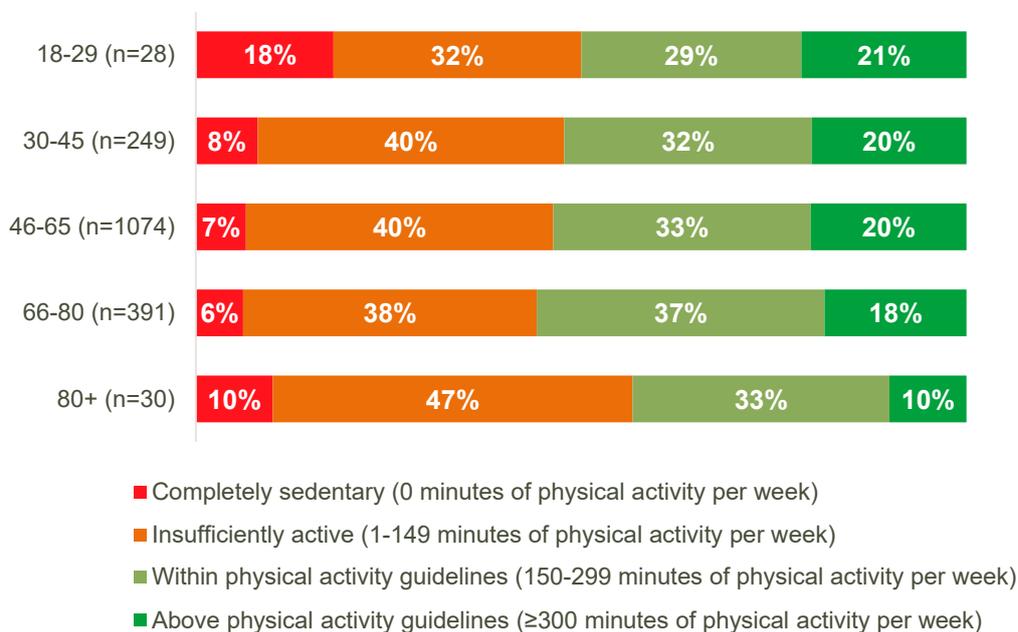
<sup>8</sup> Respondents who indicated that they would prefer not to answer this question have been removed from the percentage calculation.

Figure 35: Q21+ – I would describe my current level of leisure-time physical activity (defined as physical activity done during free time that lasted at least 10 minutes) as: (n=1867)



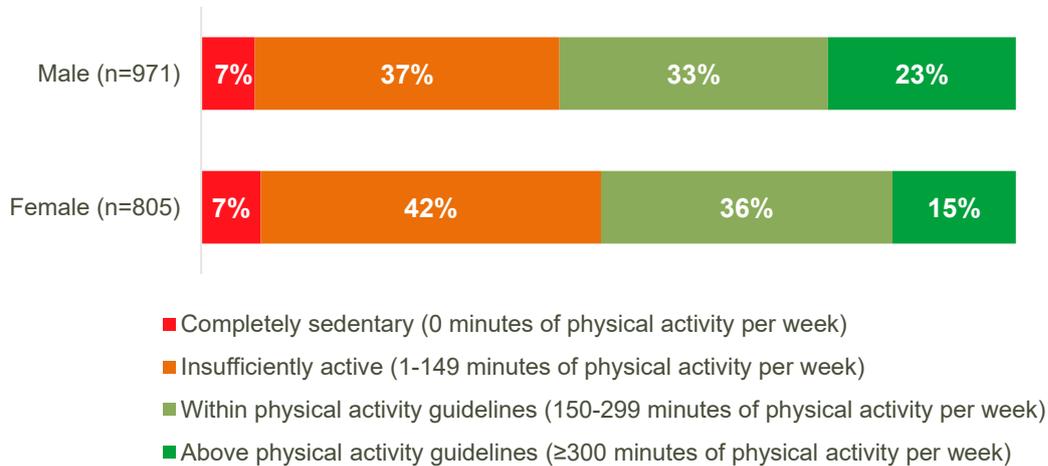
Analysis by age revealed a high proportion of all age groups reported being completely sedentary or insufficiently active. This ranged from 44% (n=173) of 66 to 80-year-olds to 57% (n=17) of those aged 80 and over – see Figure 36.

Figure 36: Q21+ – I would describe my current level of leisure-time physical activity (defined as physical activity done during free time that lasted at least 10 minutes) by Age



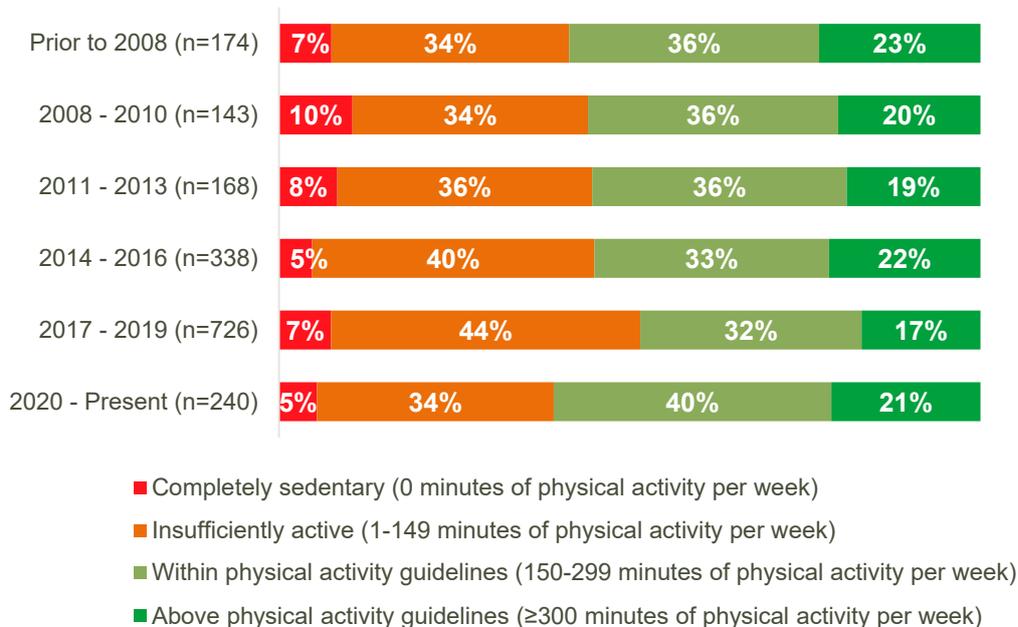
Females (49%, n=395) were more likely to report they were completely sedentary or insufficiently active than males (44%, n=427) – see Figure 37.

**Figure 37: Q21+ – I would describe my current level of leisure-time physical activity (defined as physical activity done during free time that lasted at least 10 minutes) by Gender**



As shown in Figure 38, over half of respondents (52%, n=374) who were diagnosed in 2017 to 2019 stated they were completely sedentary or insufficiently active. This is contrast to respondents who were diagnosed in 2020 to present, where 39% (n=94) stated they were completely sedentary or insufficiently active.

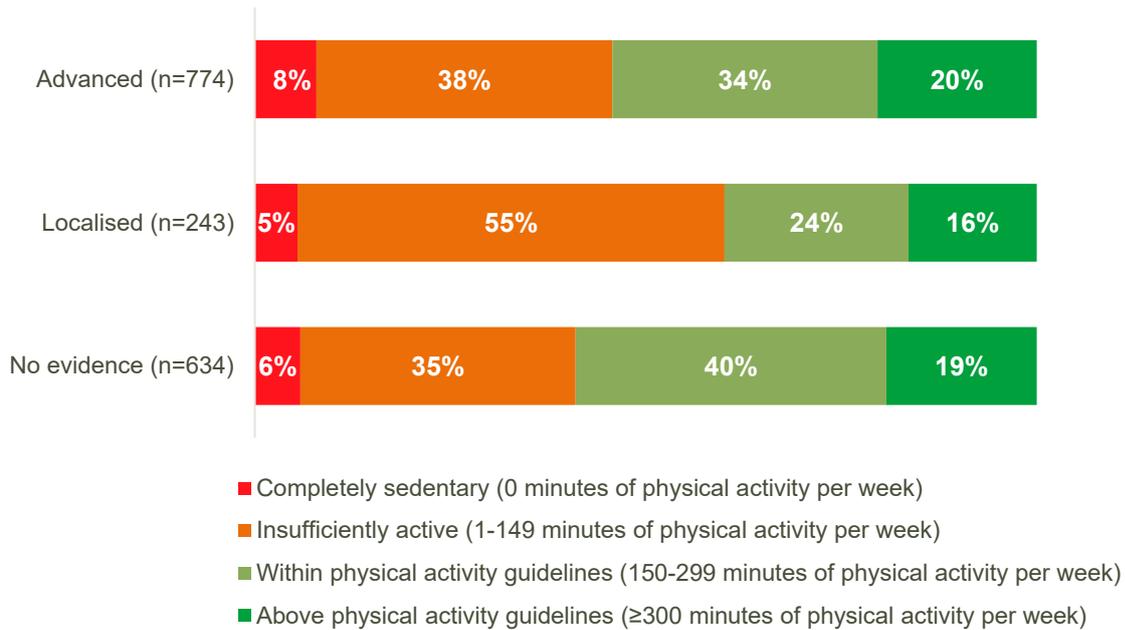
**Figure 38: Q21+ – I would describe my current level of leisure-time physical activity (defined as physical activity done during free time that lasted at least 10 minutes) by Year of diagnosis**



### Physical activity by stage of disease

Respondents who currently have no evidence of disease were most active, with 59% (n=365) reporting they were within or above physical activity guidelines. Those currently at the localised stage of disease were least active, with 40% (n=95) reporting they were within or above physical activity guidelines – see Figure 39.

Figure 39: Q21+ – I would describe my current level of leisure-time physical activity (defined as physical activity done during free time that lasted at least 10 minutes) as: by Stage of disease today

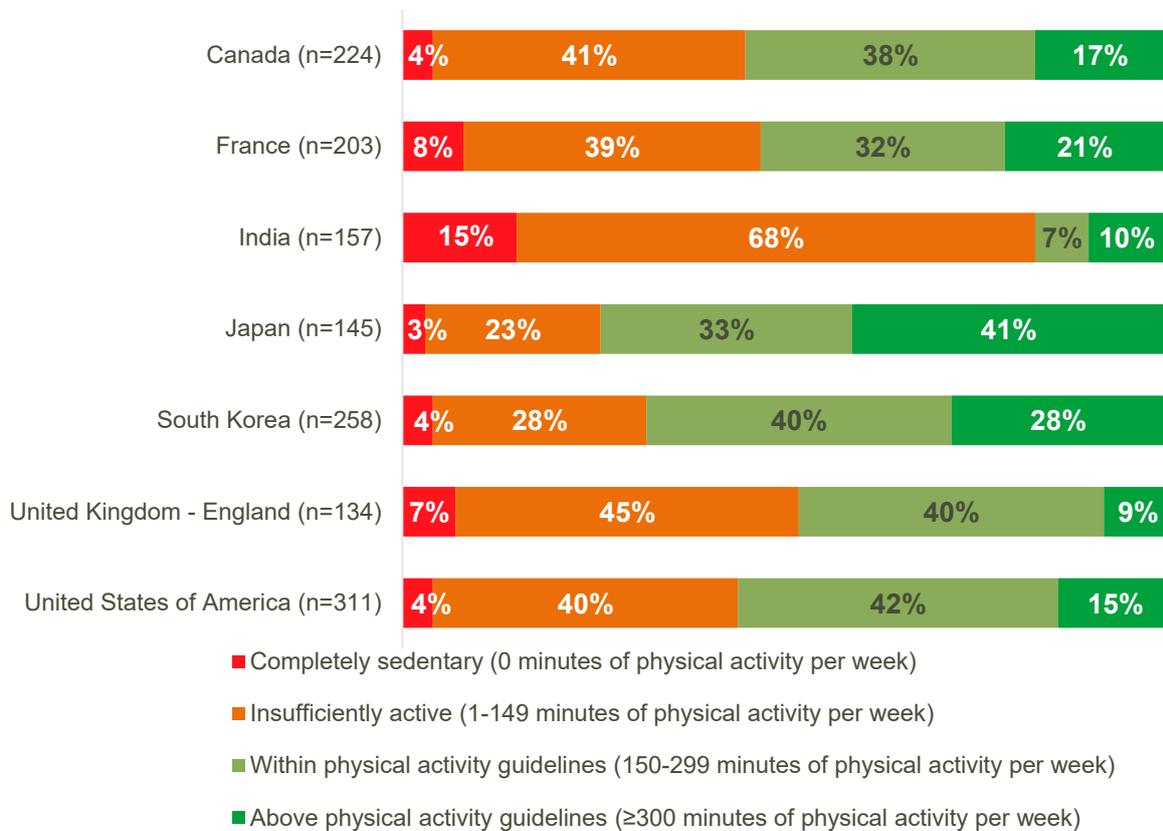


### Physical activity by country variation

There are notable differences when the feedback is considered in terms of country of residence as shown in Figure 40. Residents from Japan had the highest self-reported levels of physical activity, with 41% (n=60) of respondents indicating that they complete over 300 minutes of physical activity per week. Only 9% (n=12) of patients from UK – England and 10% (n=16) from India indicated the same.

Notably, and substantially higher than reported by respondents in other countries, 83% (n=130) of respondents from India indicated that they complete less than the recommended amount of physical activity per week.

Figure 40: Q21+ – I would describe my current level of leisure-time physical activity (defined as physical activity done during free time that lasted at least 10 minutes) as: by Country of residence



## Psychosocial wellbeing

It is important to recognise the emotional, psychological and social impact of a diagnosis. The IKCC survey 2020 probed each of the following potential impacts to patient wellbeing:

- General anxiety
- Disease-related anxiety
- Fear of dying
- Fear of the cancer/growth coming back (recurrence)
- Depression
- Isolation
- Changes in relationships with loved ones, friends, or co-workers
- Difficulty in daily living, on the job or in school
- Stress related to financial issues
- Loss/reduction in employment
- Difficulty navigating the healthcare system
- Problems getting health or life insurance coverage
- Concerns about body image/changes in physical appearance
- Sexuality

Each of these categories have been considered in the following subsections: by current stage of disease (localised, advanced and no evidence/cured) and globally compared to individual countries.

### General anxiety

Nearly two-thirds of respondents (62%, n=151) with localised kidney cancer or kidney growth stated they always/very often felt general anxiety. As shown in Figure 41, this is notably higher than respondents who at the time of responding were at an advanced stage (40%, n=308) or who had no evidence of kidney cancer or growth (38%, n=236).

Figure 41: Q22a – How often have the following impacted your sense of emotional well-being since your diagnosis? – GENERAL ANXIETY by Stage of disease today

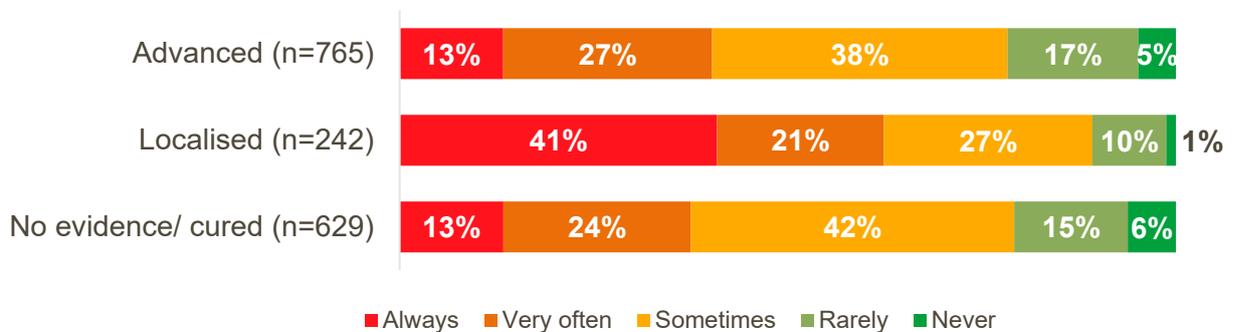
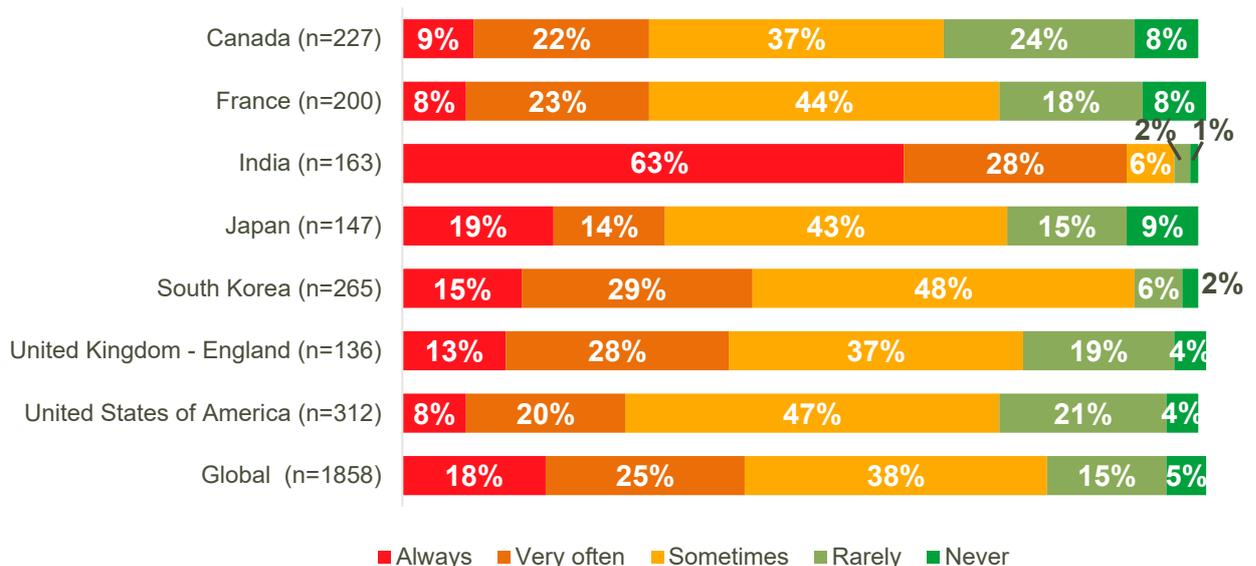


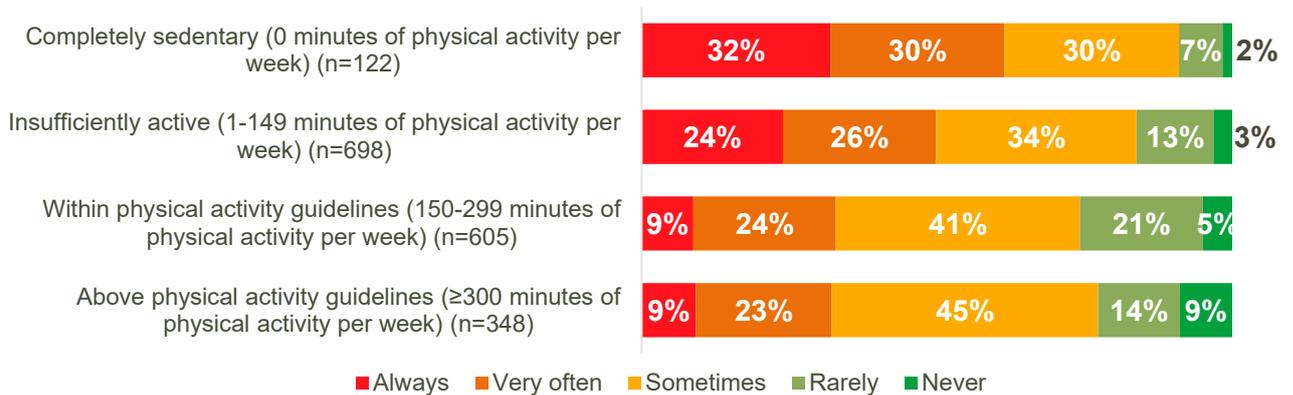
Figure 42 indicates that self-reports of general anxiety were unusually high from respondents in India. 91% (n=149) of respondents reported that they very often/always felt general anxiety.

Figure 42: Q22a – How often have the following impacted your sense of emotional well-being since your diagnosis? – GENERAL ANXIETY by Country of residence



61% (n=75) of respondents who stated that their level of physical activity was completely sedentary indicated that they always/very often experienced general anxiety. This was notably higher than for respondents who exercised within (33%, n=199) and above (32%, n=112) physical activity guidelines – See Figure 43.

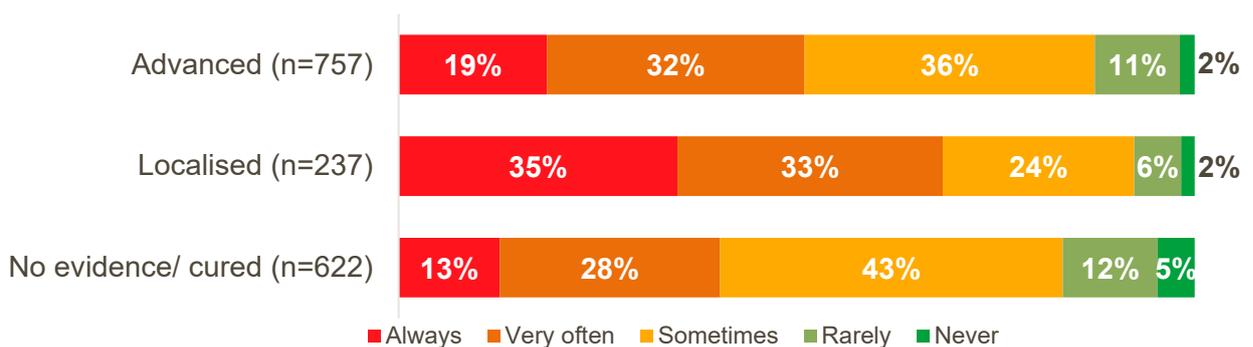
**Figure 43: Q22a – How often have the following impacted your sense of emotional well-being since your diagnosis? – GENERAL ANXIETY by Level of physical activity**



### Disease-related anxiety

Respondents with no evidence of kidney cancer or growth were least likely to self-report always/very often feeling of disease related anxiety (40%, n=251) compared to 51% of respondents at the advanced stage (n=386) and 68% of respondents with localised kidney cancer or growth (n=162) – see Figure 44.

**Figure 44: Q22b – How often have the following impacted your sense of emotional well-being since your diagnosis? – DISEASE-RELATED ANXIETY by Stage of disease today**



Reported disease specific anxiety was unusually high in respondents from India – see Figure 45, where 88% (n=141) of respondents reported that they very often/always felt disease-specific anxiety. Likewise, respondents from South Korea also reported comparatively high levels of anxiety. Only 1% (n=3) of respondents said that they never had disease-specific anxiety. 58% (n=148) indicated that their anxiety was always/very often present.

Figure 45: Q22b – How often have the following impacted your sense of emotional well-being since your diagnosis? – DISEASE-RELATED ANXIETY by Country of residence

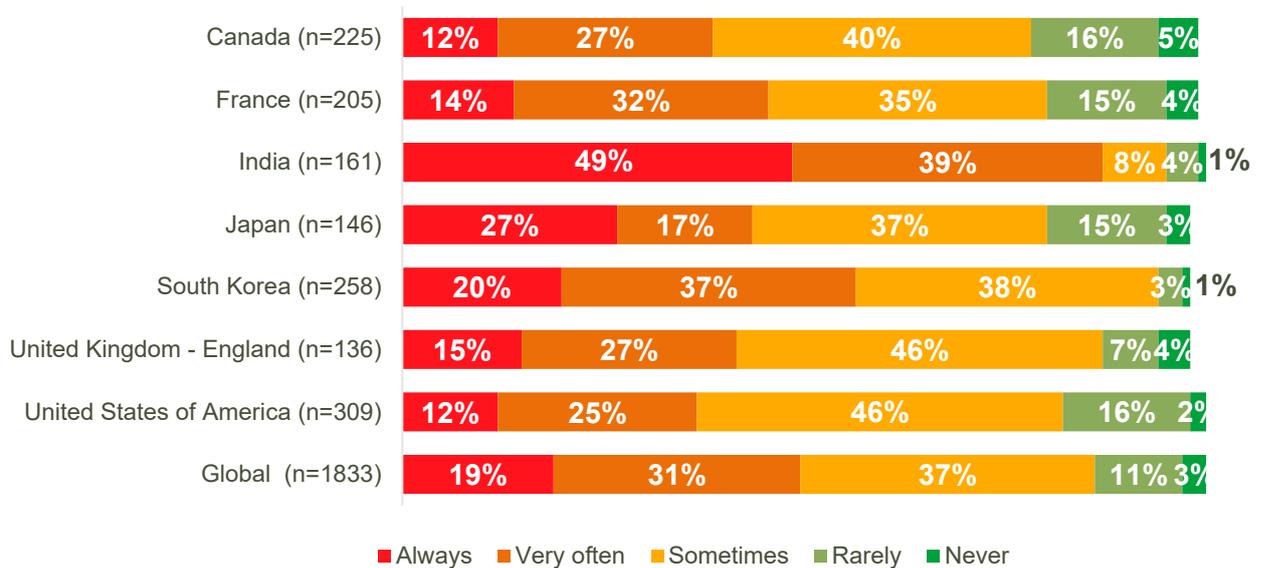
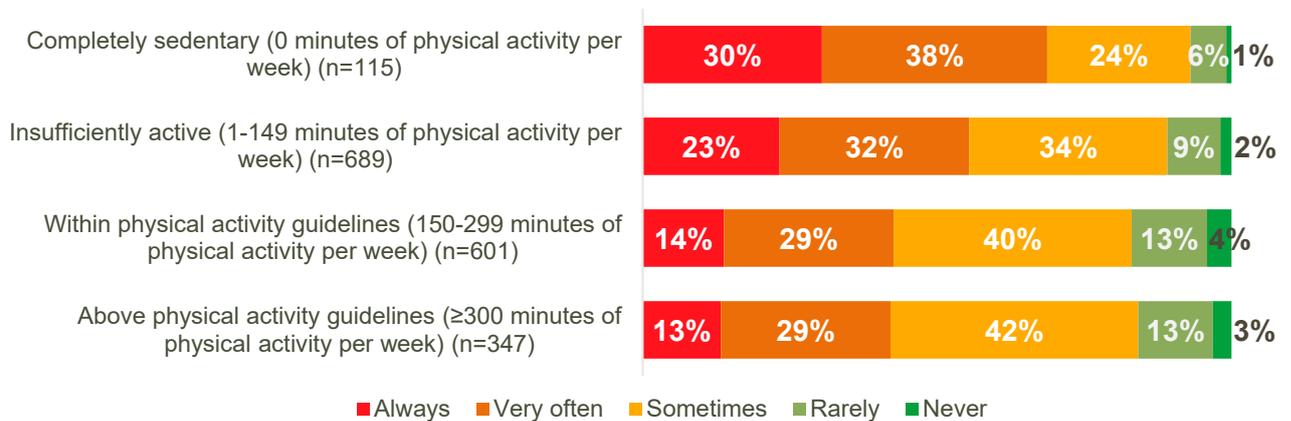


Figure 46 shows the majority of respondents who reported being completely sedentary (69%, n=79) or insufficiently active (55%, n=382) experienced disease related anxiety always or very often. This contrasts with respondents who reported their physical activity as within (43%, n=256) or above (42%, n=146) guidelines.

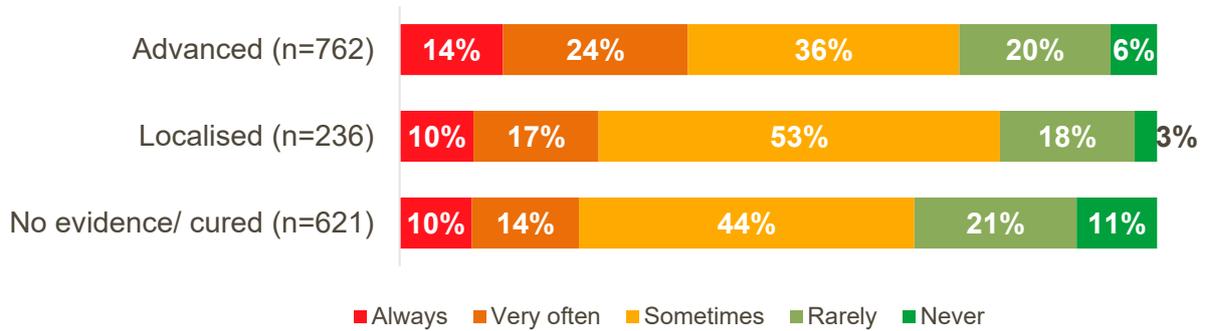
Figure 46: Q22b – How often have the following impacted your sense of emotional well-being since your diagnosis? – DISEASE-RELATED ANXIETY by Level of physical activity



### Fear of dying

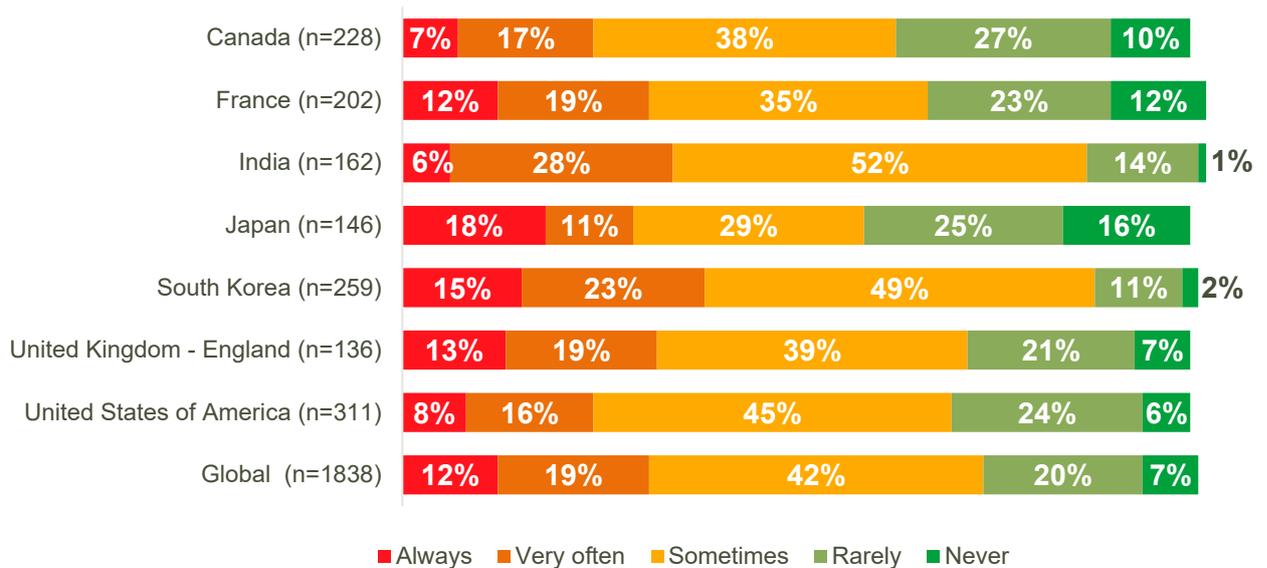
More than one third of respondents at the advanced stage (38%, n=290) reported always/very often experiencing fear of dying – see Figure 47. This is compared to 26% of respondents at the localised stage (n=62) and 24% of respondents with no evidence of kidney cancer/growth (n=147).

Figure 47: Q22c – How often have the following impacted your sense of emotional well-being since your diagnosis? – FEAR OF DYING by Stage of disease today



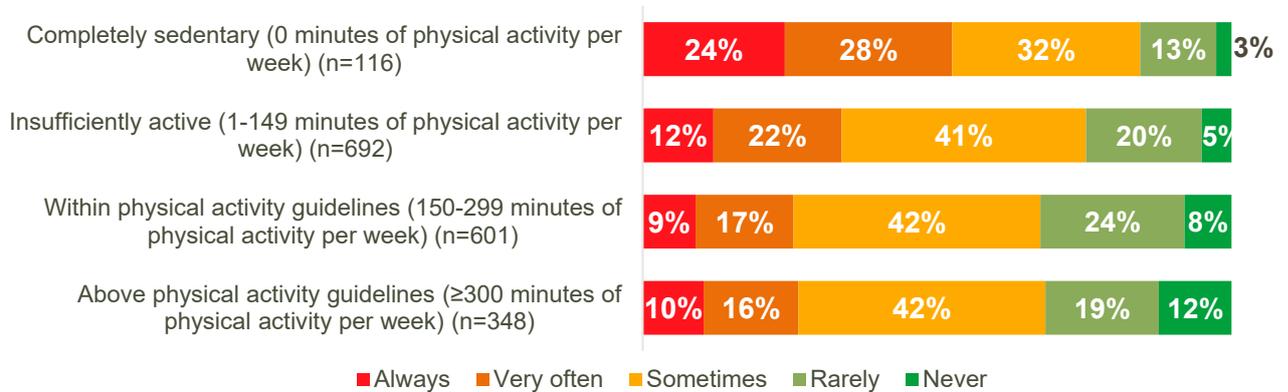
Overall fear of dying was generally a much lower reported anxiety than others that were explored as part of the 2020 survey. In fact, 16% (n=23) of respondents in Japan indicated that they never experienced this emotional impact – see Figure 48.

Figure 48: Q22c – How often have the following impacted your sense of emotional well-being since your diagnosis? – FEAR OF DYING by Country of residence



As outlined in Figure 49, over half (53%, n=61) of respondents who reported that they were completely sedentary indicated that they always/very often had a fear of dying. This is compared to just over a quarter (26%) of respondents who exercised within (n=100) or above (n=92) physical activity guidelines.

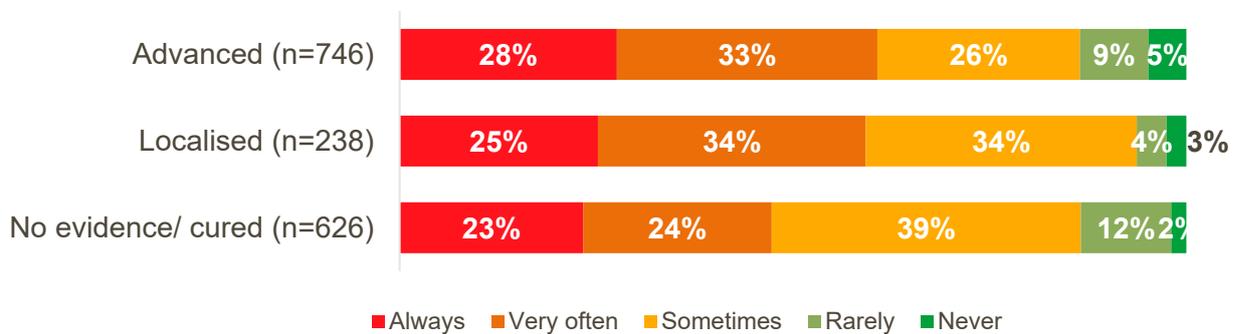
**Figure 49: Q22c – How often have the following impacted your sense of emotional well-being since your diagnosis? – FEAR OF DYING by Level of physical activity**



### Fear of the cancer/growth coming back (recurrence)

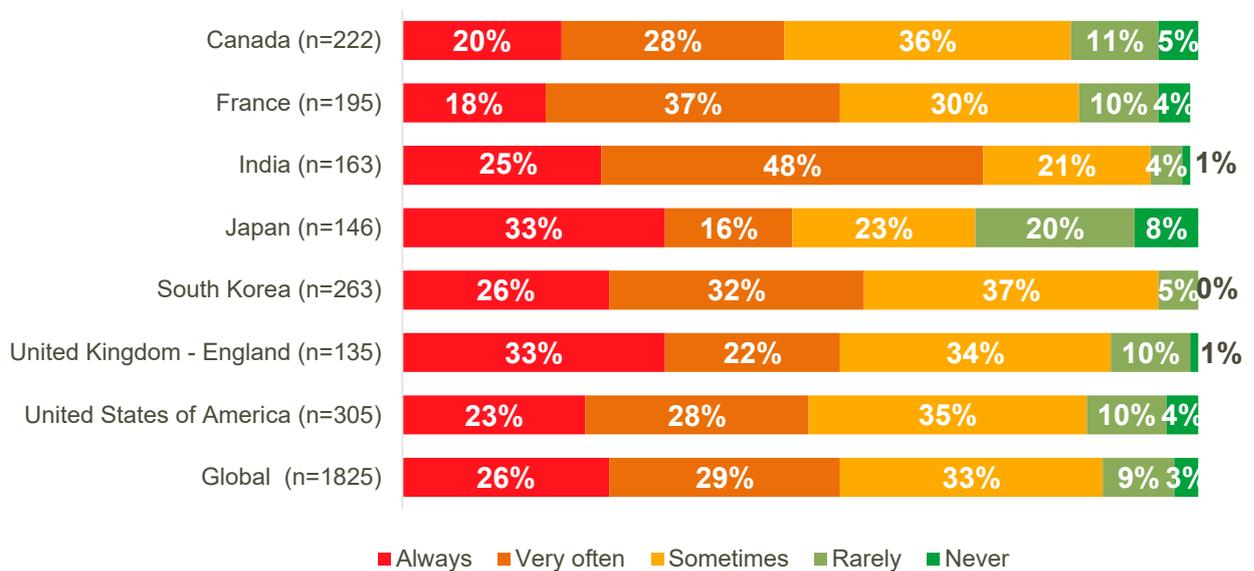
As indicated in Figure 50, fear of the cancer/growth coming back (recurrence) was least likely to be reported by respondents with no evidence of kidney cancer/growth (47%, n=296) compared to 61% at the advanced stage (n=453) and 59% at the localised stage (n=141).

**Figure 50: Q22d – How often have the following impacted your sense of emotional well-being since your diagnosis? – FEAR OF THE CANCER/GROWTH COMING BACK (RECURRENCE) by Stage of disease today**



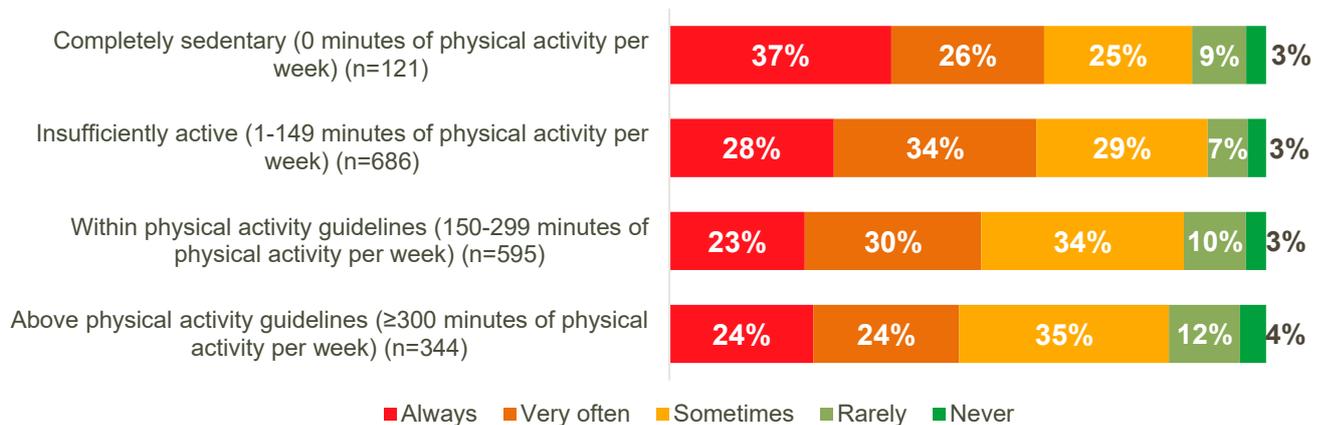
Globally, just over half of respondents reported always/very often having the fear of recurrence (55%, n=1003). This appears to be consistent across the different countries – see Figure 51. Although, again, the fear is reported as slightly more pronounced from residents in India. 74% of respondents from this country indicated the fear was always/very often (n=120).

**Figure 51: Q22d – 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**



Half of respondents who exercise within or above physical guidelines (52%, n=311 and 49%, n=167 respectively) reported always/often experiencing fear of recurrence. This rose to two thirds for respondents who are completely sedentary or insufficiently active (63%, n=76 and 62%, n=422 respectively) – See Figure 52.

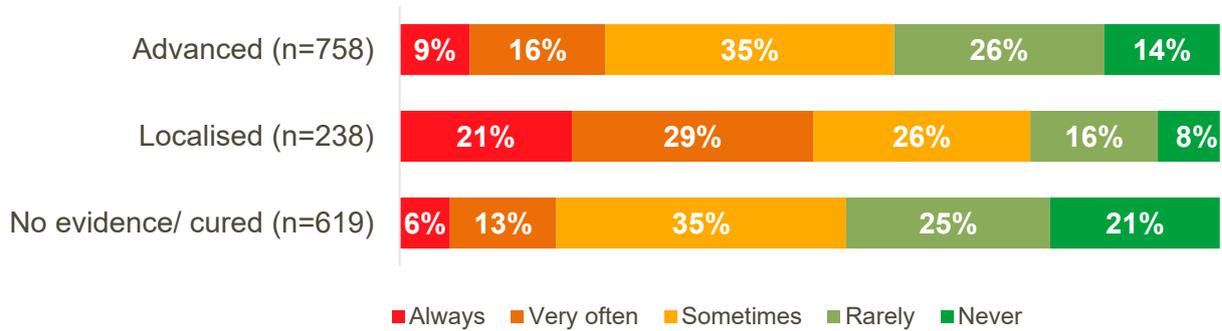
**Figure 52: Q22d – How often have the following impacted your sense of emotional well-being since your diagnosis? – FEAR OF THE CANCER/GROWTH COMING BACK (RECURRENCE) by Level of physical activity**



## Depression

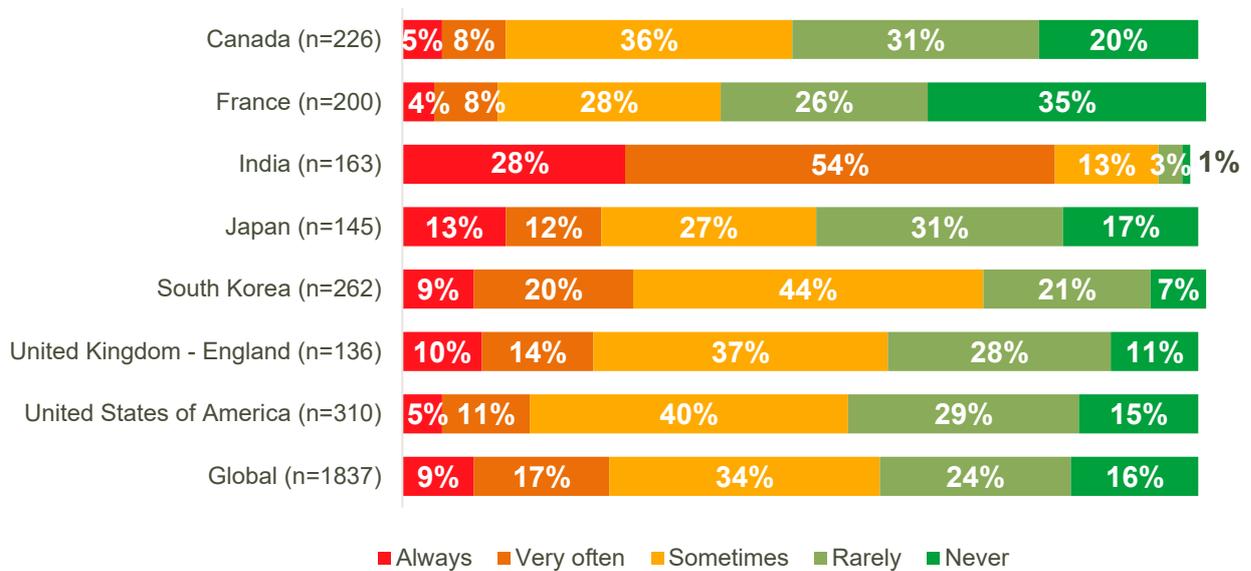
As can be seen in Figure 53, respondents at the localised stage (50%, n=120) were twice as likely to report experiencing depression always or very often than respondents at the advanced stage (25%, n=190) and respondents with no evidence of kidney cancer/growth (19%, n=118).

Figure 53: Q22e – How often have the following impacted your sense of emotional well-being since your diagnosis? – FEAR OF THE CANCER/GROWTH COMING BACK (RECURRENCE) by Stage of disease today



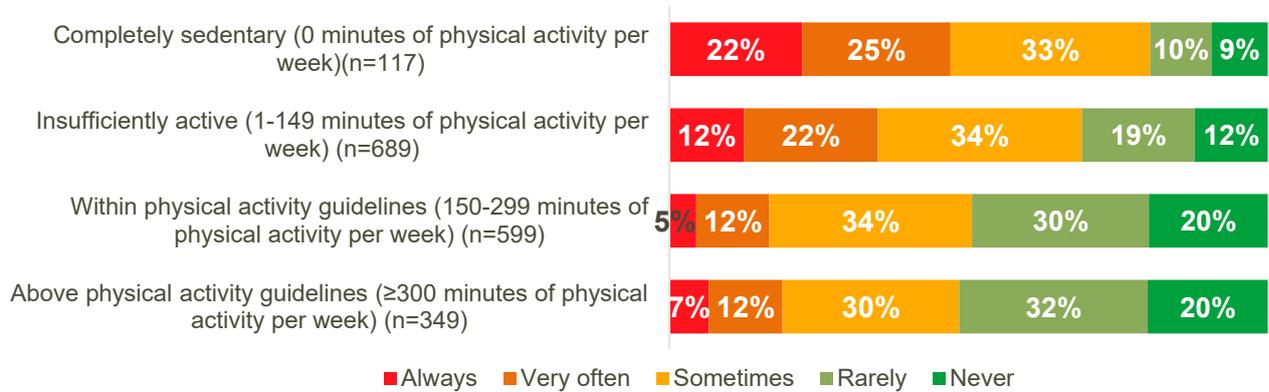
Globally, only 26% (n=480) of respondents indicated that they always/very often experienced depression. This makes the result from India all the more striking. 82% of respondents (n=134) suggested that they always/very often had depression. Reported depression is relatively low in France. 35% of respondents (n=70) suggested that they never experienced depression. See Figure 54 for a full breakdown by country.

Figure 54: Q22e – How often have the following impacted your sense of emotional well-being since your diagnosis? – DEPRESSION by Country of residence



One in five respondents who reported their level of physical activity as being within guidelines (20%, n=119) or above guidelines (20%, n=70) stated that they never experience depression. In contrast, more than one in five respondents who are completely sedentary (22%, n=26) reported always being impacted by depression – see Figure 55.

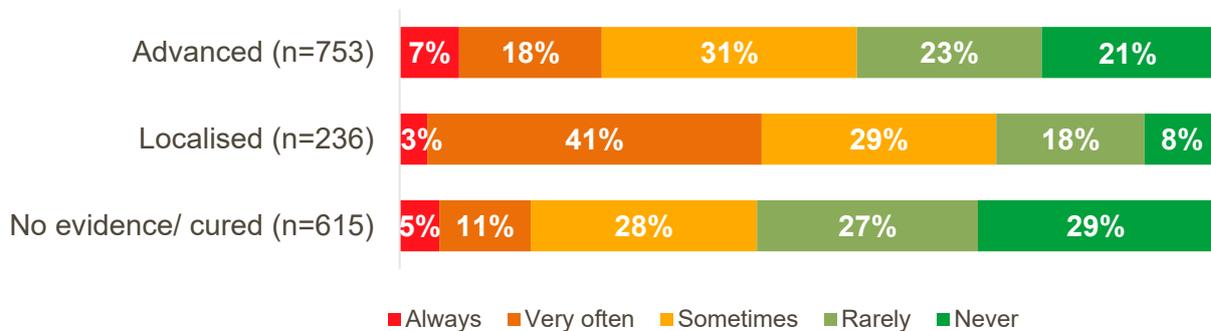
**Figure 55: Q22e – How often have the following impacted your sense of emotional well-being since your diagnosis? – DEPRESSION by Level of physical activity**



### Isolation

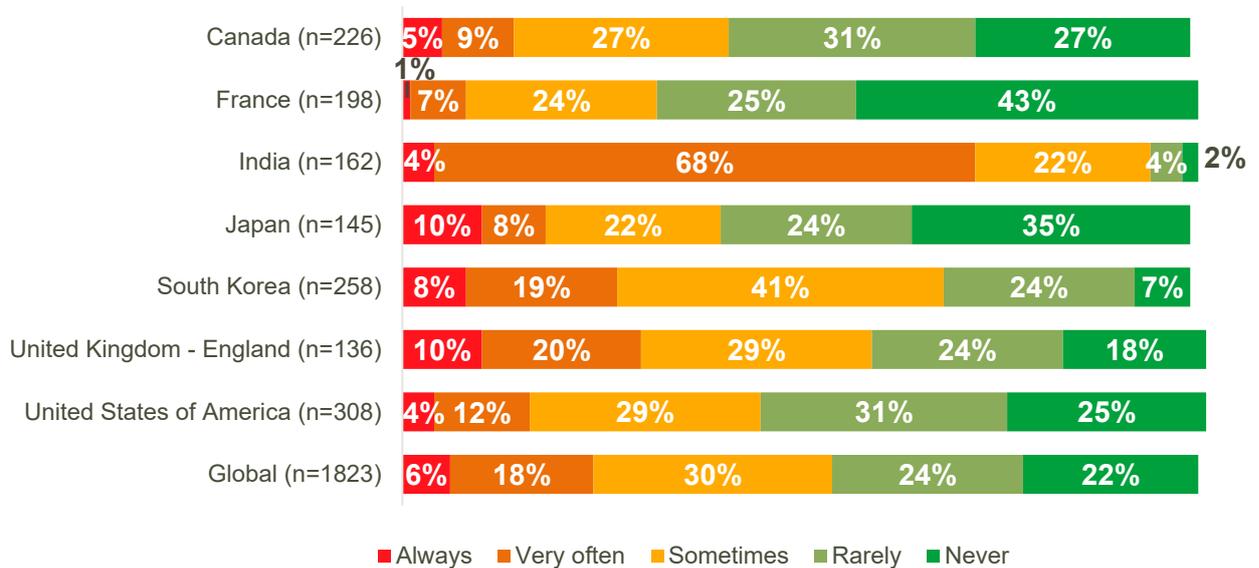
Isolation was reported as being a much more prevalent experience for respondents with localised kidney cancer/growth, with 44% reporting they always or very often felt isolated (n=105). As shown in Figure 56, this is notably higher than respondents at the advanced stage (25%, n=187) and in respondents with no evidence of disease (16%, n=99).

**Figure 56: Q22f – How often have the following impacted your sense of emotional well-being since your diagnosis? – ISOLATION by Stage of disease today**



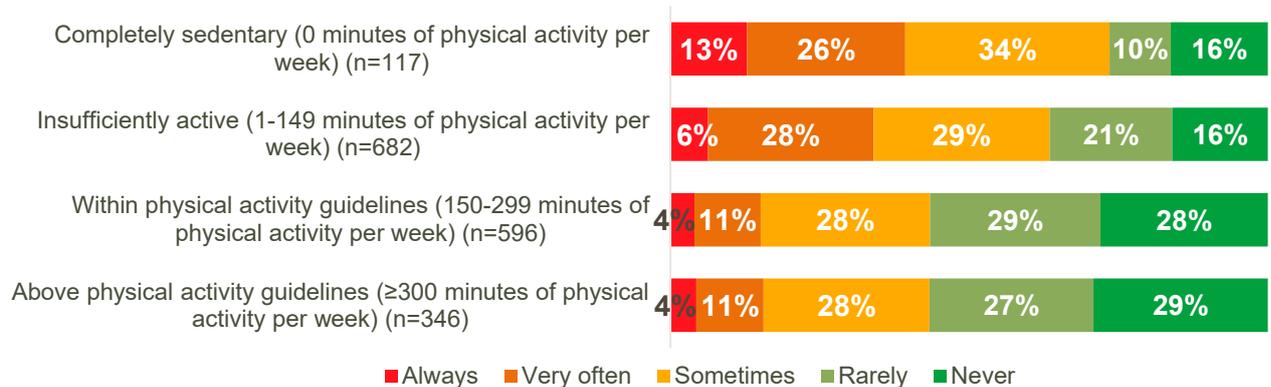
Both residents from France and Japan reported comparatively low levels of concern regarding worries of isolation. 43% (n=85) and 35% (n=51) of respondents respectively reported never feeling isolation. Again, respondents in India have flagged high levels of concern, with 72% (n=117) reporting they always/often experience isolation. See Figure 57 for full details.

Figure 57: Q22f – How often have the following impacted your sense of emotional well-being since your diagnosis? – ISOLATION by Country of residence



Respondents who undertake regular exercise either above guidelines (57%, n=196) or within guidelines (57%, n=337) were more than twice as likely to state they rarely/never experience isolation than respondents who reported being completely sedentary (26%, n=31) – See Figure 58

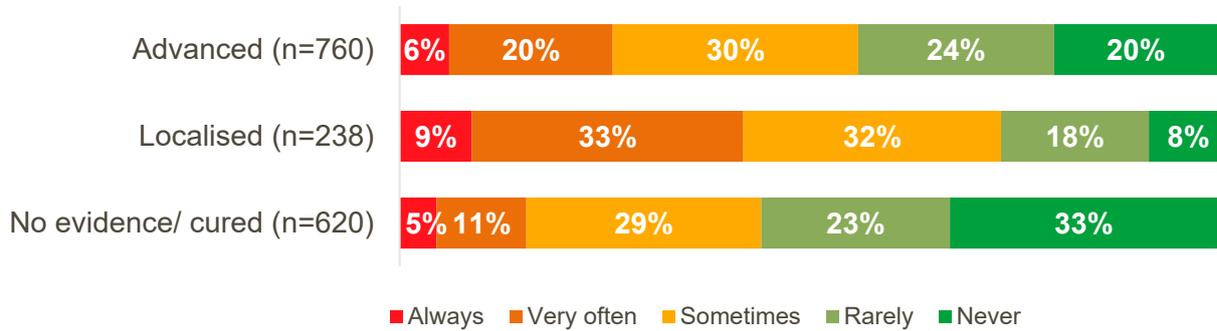
Figure 58: Q22f – How often have the following impacted your sense of emotional well-being since your diagnosis? – ISOLATION by Level of physical activity



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

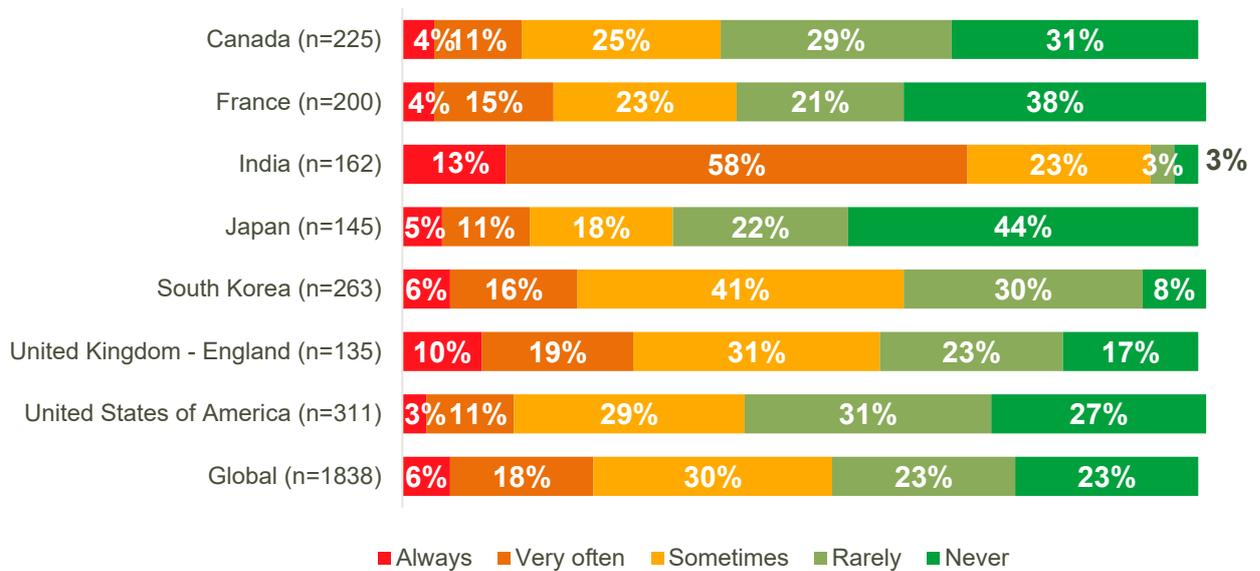
Respondents with no evidence of kidney cancer/growth were most likely to report they have never experienced changed in relationships with loved ones, friends and co-workers since their diagnosis (33%, n=203) – see Figure 59. This is in contrast with respondents at the localised stage, where only 8% stated they have never experienced changed in relationships with loved ones, friends and co-workers since their diagnosis (n=20).

Figure 59: Q22g – 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 Stage of disease today



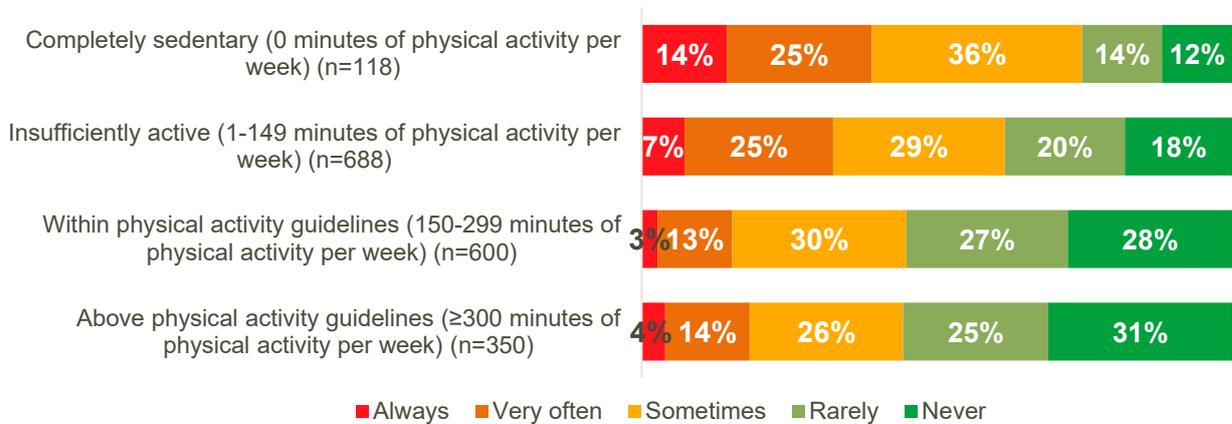
On average, just under 1 in 4 respondents (23%, n=414) globally reported never being concerned with changes in relationships. 44% (n=64) of respondents from Japan reported that this was never a concern. Conversely, only 3% (n=5) of respondents from India said that this was the case and 71% (n=115) suggested that this was always/very often a concern – see Figure 60.

Figure 60: Q22g – How often have the following impacted your sense of emotional well-being since your diagnosis? – CHANGES IN RELATIONSHIPS WITH LOVED ONES, FRIENDS OR CO-WORKER by Country of residence



As shown in Figure 61, changes in relationships with loved ones was of less concern to respondents who exercised above physical activity guidelines, with 31% (n=109) reporting they had never experienced this type of anxiety. This contrasts with 12% of respondents (n=14) who reported being completely sedentary.

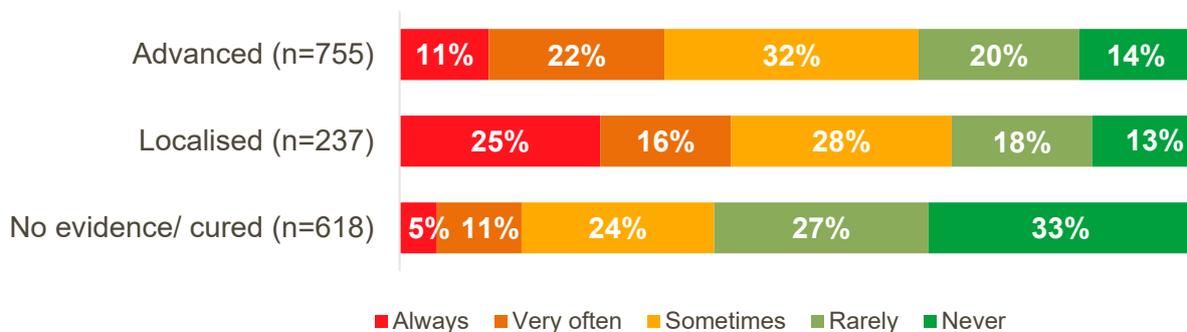
**Figure 61: Q22g – How often have the following impacted your sense of emotional well-being since your diagnosis? – CHANGES IN RELATIONSHIPS WITH LOVED ONES, FRIENDS OR CO-WORKERS by Level of physical activity**



### Difficulty in daily living, on the job or in school

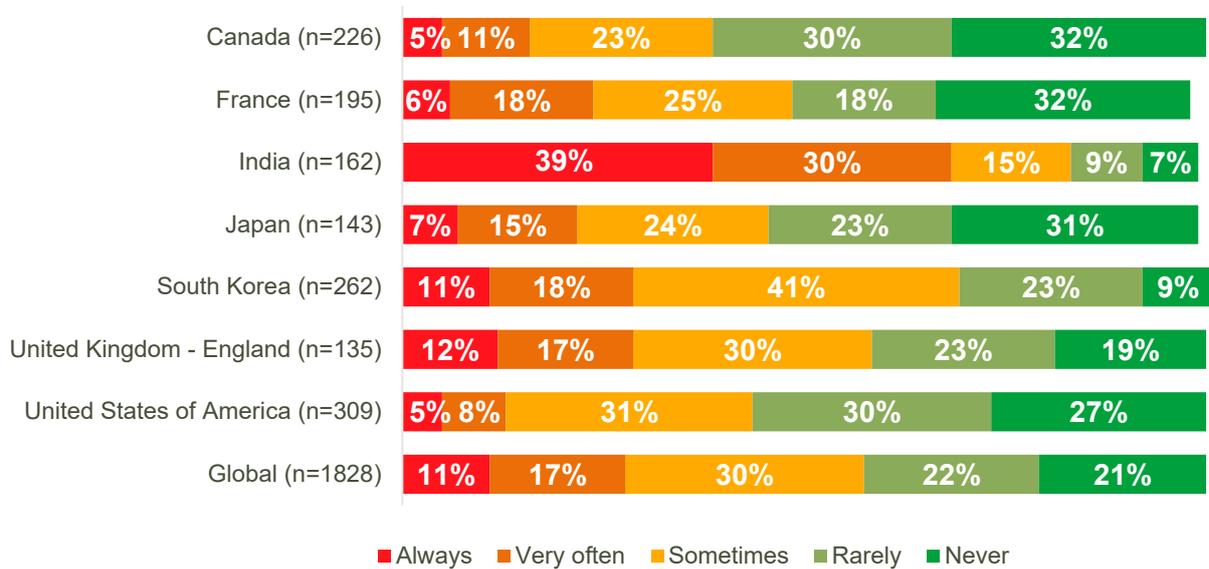
Respondents at the advanced and localised stage of their diagnosis were most likely to report experiencing difficulty in daily living, on the job or in school. As shown in Figure 62, 33% of respondents at the advanced stage (n=252) and 42% of respondents at the localised stage (n=99) reported always or very often experiencing this difficulty.

**Figure 62: Q22h – 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 Stage of disease today**



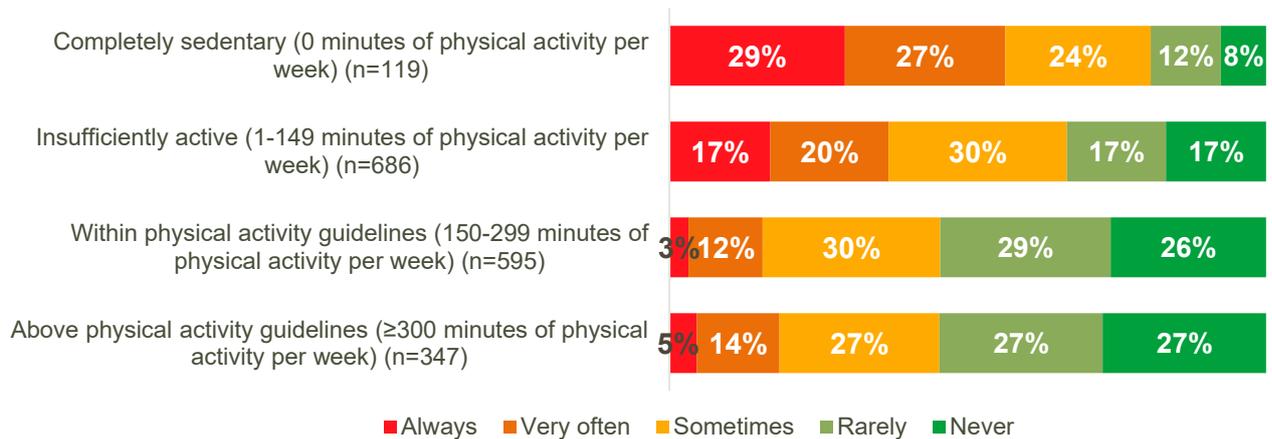
Almost 4 people in 10 (39%, n=63) who are residents in India indicated that they always have difficulty in daily living. This is 27% higher than the second highest reporting country, United Kingdom – England (12%, n=16) – see Figure 63.

**Figure 63: Q22h – 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**



Difficulty in daily living was a more prevalent concern for respondents who reported being completely sedentary, with 56% (n=67) reporting they always/very often experienced this, compared to just 16% (n=93) of respondents within physical activity guidelines – See Figure 64.

**Figure 64: Q22h – 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 Level of physical activity**



### Stress related to financial issues

Stress related to financial stress was of most concern to respondents at the localised stage, with only 10% of respondents (n=23) in this category stating they have never experienced this impact since their diagnosis. As can be seen in Figure 65, this is notably lower than respondents in the advanced stage (26%, n=195) and no evidence stage (34%, n=214).

Figure 65: Q22i – How often have the following impacted your sense of emotional well-being since your diagnosis? – STRESS RELATED TO FINANCIAL ISSUES by Stage of disease today

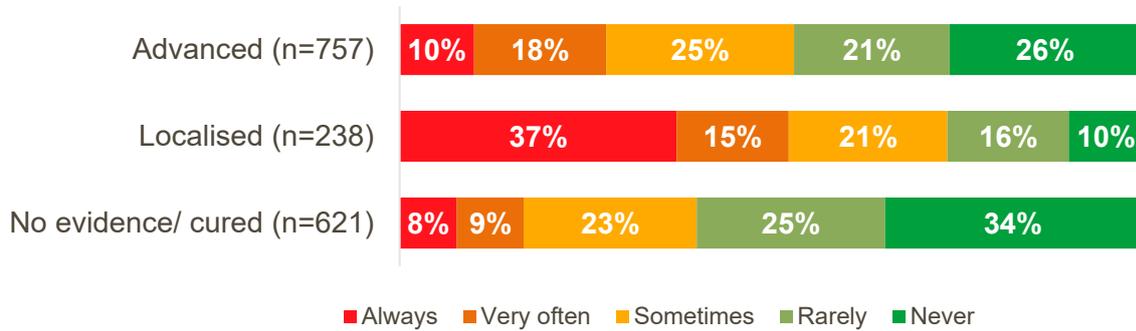
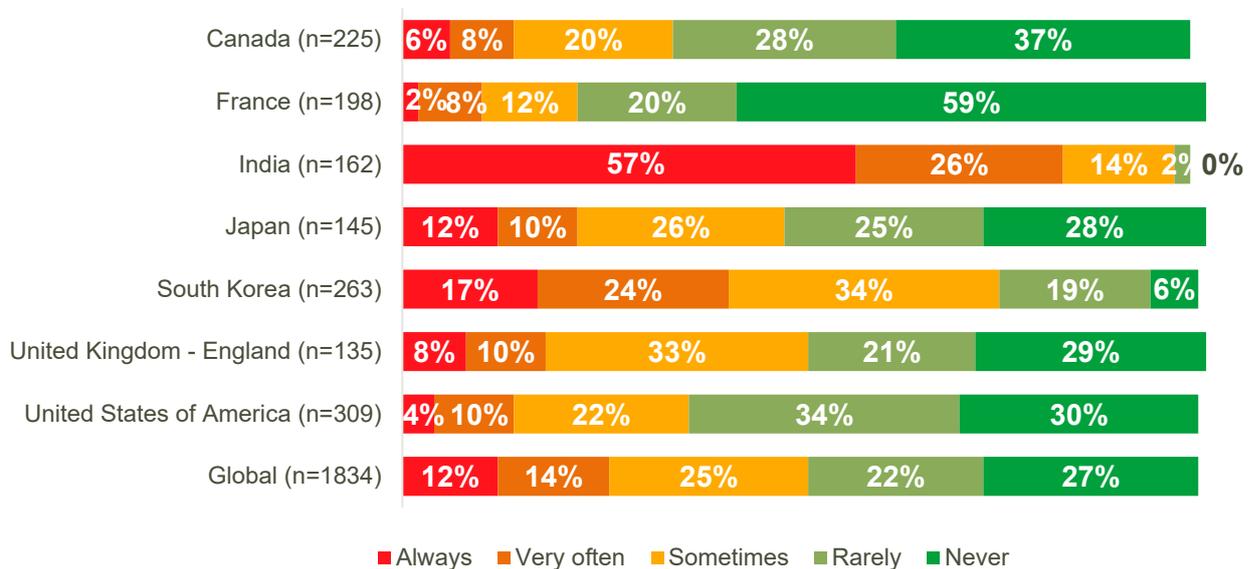


Figure 66 indicates respondents experiences of financial-related stress, by country.

Respondents in France reported the best experience regarding low levels of stress relating to financial issues. 59% (n=117) indicated that they never had this emotional concern. The opposite is true for respondents in India. 57% (n=93) reported that this was always a concern, and nobody said that this was never a concern.

The result from India is very striking but the feedback from South Korea should not be overlooked. Only 6% of respondents (n=17) reported that stress related to financial issues was never a concern and 41% (n=107) indicated that it was always/very often a worry.

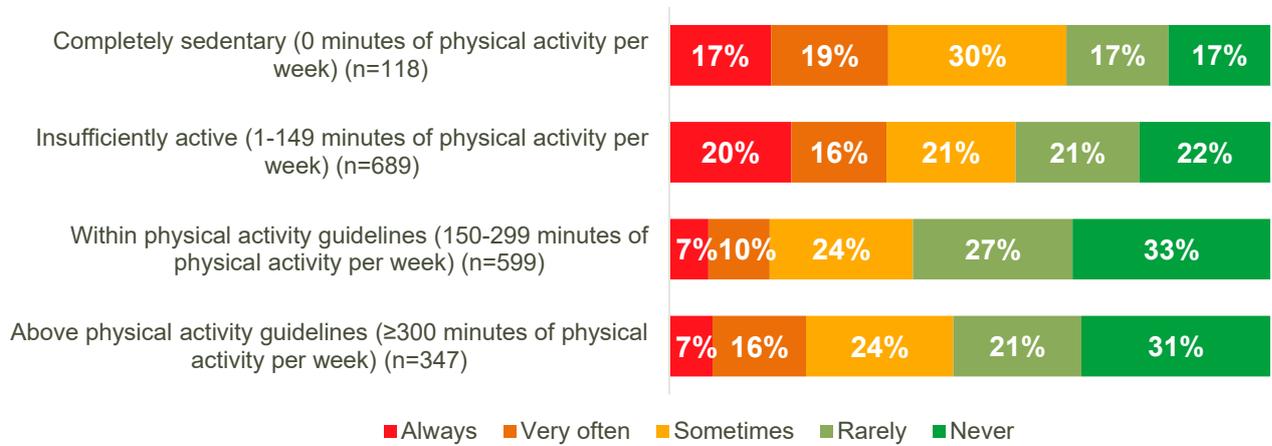
Figure 66: Q22i – How often have the following impacted your sense of emotional well-being since your diagnosis? – STRESS RELATED TO FINANCIAL ISSUES by Country of residence



Those respondents who reported being completely sedentary or in Insufficiently active were most likely to report that they always/ very often experienced stress related to financial issues. This accounted for 36% (n=43) of those who indicated that they are completely sedentary and 34% (n=234) of those who are insufficiently active.

As can be seen in Figure 67, this is notably higher than respondents who were within physical activity guidelines (26%, n=154) and above (26%, n=92).

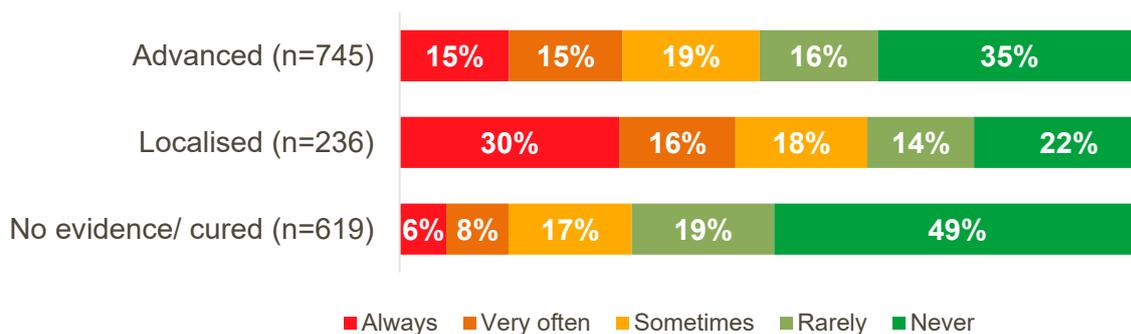
**Figure 67: Q22i – How often have the following impacted your sense of emotional well-being since your diagnosis? – STRESS RELATED TO FINANCIAL ISSUES by Level of physical activity**



### Loss/reduction in employment

Since their diagnosis, loss/reduction in employment has been of least concern to respondents at the no evidence stage, with 49% of respondents (n=306) in this category stating they have never experienced this concern. In contrast, loss/reduction in employment has been of most concern to respondents at the localised stage of their diagnosis, with only 22% of respondents (n=53) stating this has never been a concern to them. See Figure 68 for full breakdown.

**Figure 68: Q22j – How often have the following impacted your sense of emotional well-being since your diagnosis? – LOSS/REDUCTION IN EMPLOYMENT by Stage of disease today**



Overall loss/reduction in employment appears to be a much lower concern. Globally, 4 in 10 (39%, n=703) said that this was never a concern. However, there are notable variants to this by country – see Figure 69 – whereby both residents in India and South Korea report this as being a higher concern than in other countries.

Figure 69: Q22j – How often have the following impacted your sense of emotional well-being since your diagnosis? – LOSS/REDUCTION IN EMPLOYMENT by Country of residence

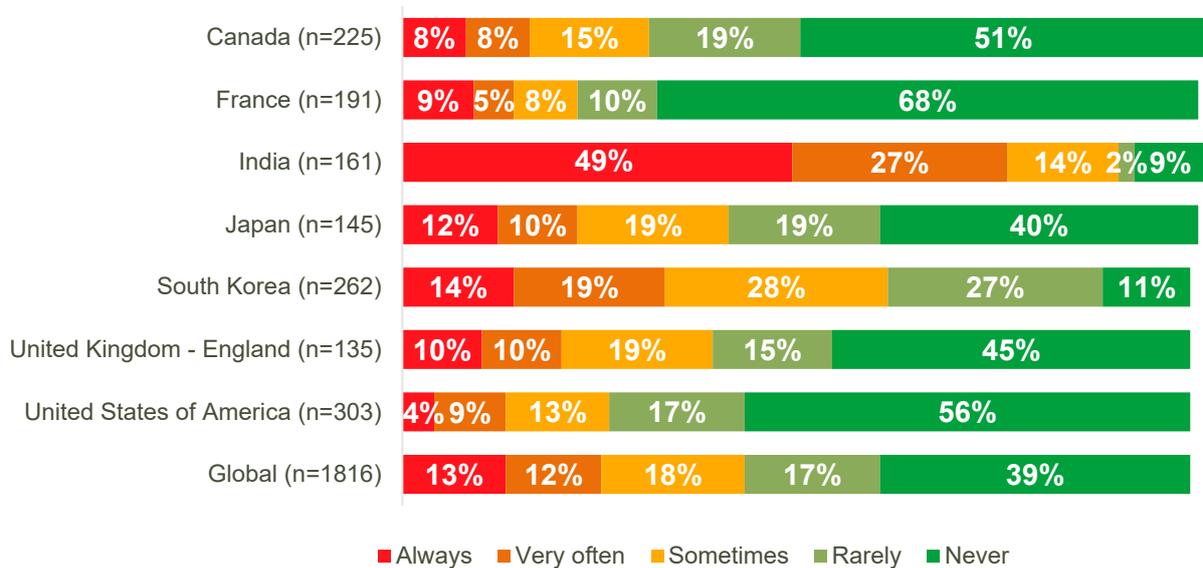
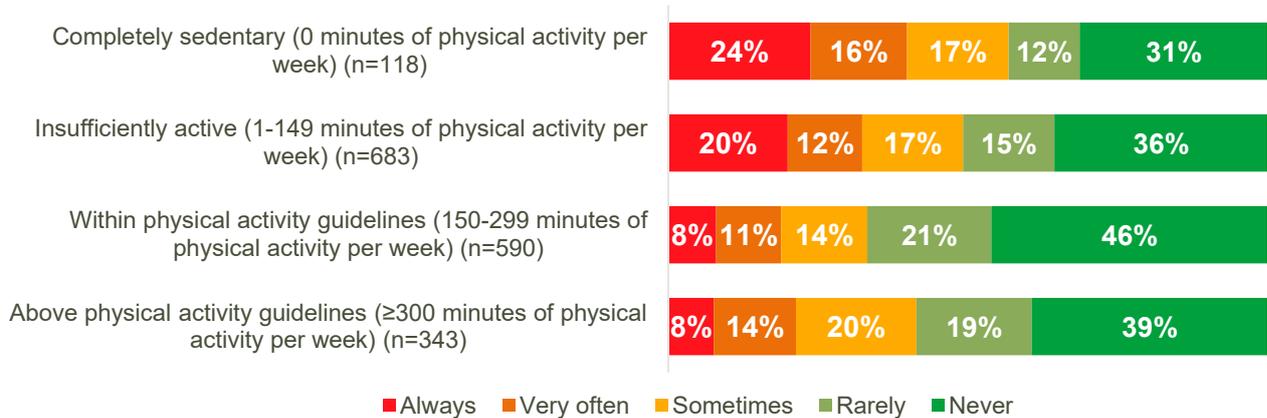


Figure 70 outlines that 40% (n=47) of those that reported being completely sedentary and 32% (n=221) of those that reported being insufficiently active indicated that they always/very often worried about loss/reduction in employment. This is compared to 19% (n=111) of those that reported exercising within physical activity guidelines.

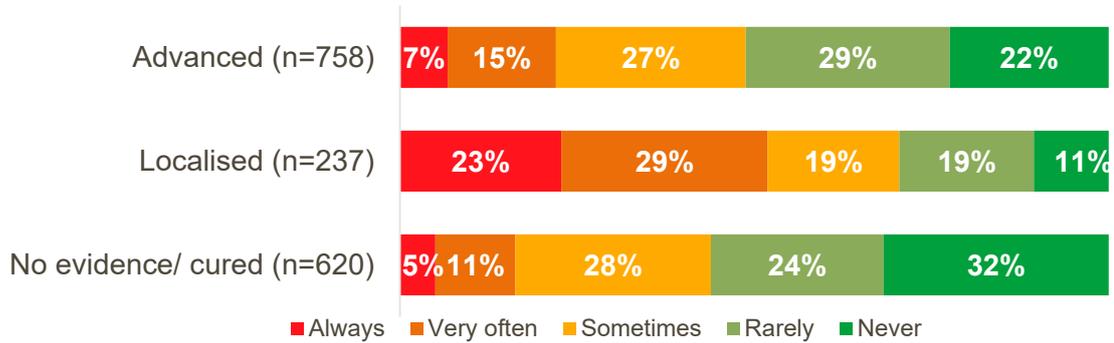
Figure 70: Q22j – How often have the following impacted your sense of emotional well-being since your diagnosis? – LOSS/REDUCTION IN EMPLOYMENT by Level of physical activity



### Difficulty navigating the healthcare system

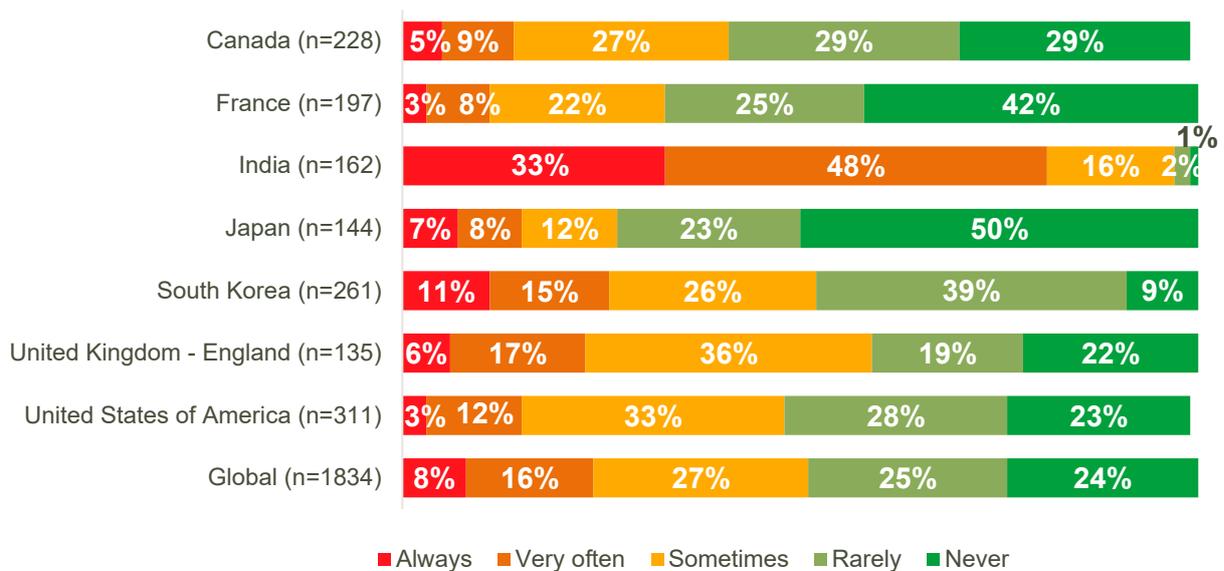
More than half of respondents at the localised stage (52%, n=123) stated they always or very often experience concern about difficulty navigating the healthcare system. As shown in Figure 71, this is considerably higher than reported by respondents at the advanced stage (22%, n=167) and no evidence stage (16%, n=101).

Figure 71: Q22k – How often have the following impacted your sense of emotional well-being since your diagnosis? – DIFFICULTY NAVIGATING THE HEALTHCARE SYSTEM by Stage of disease today



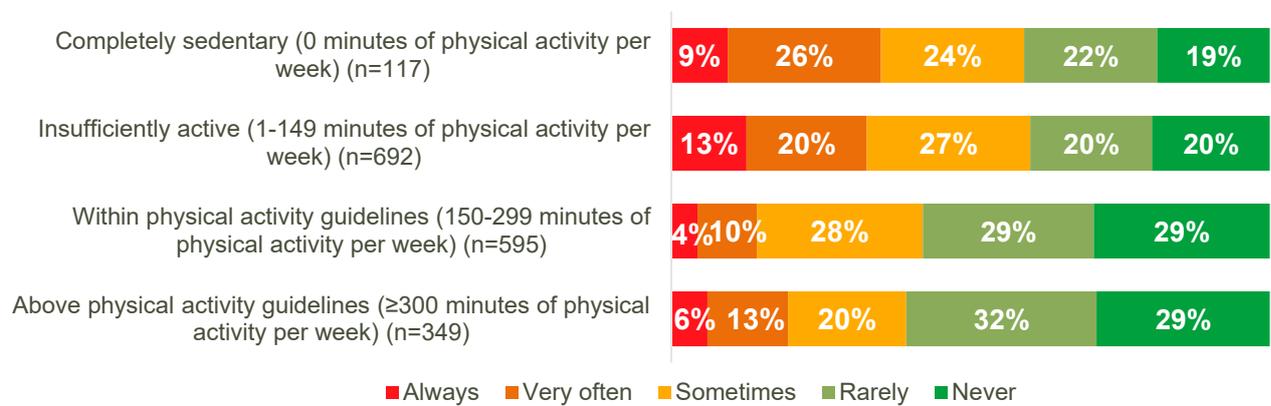
Difficulty navigating the healthcare system appears to only be a great concern amongst respondents from India – see Figure 72. Here, 81% (n=131) of respondents said that this was always/very often an emotional issue, compared to 24% (n=437) globally.

Figure 72: Q22k – How often have the following impacted your sense of emotional well-being since your diagnosis? – DIFFICULTY NAVIGATING THE HEALTHCARE SYSTEM by Country of residence



More than six in ten respondents (61%, n=212) who reported their physical activity level as being above guidelines stated that they rarely/never experience difficulty navigating the healthcare system. This is notably higher than the 40% (n=277) of insufficiently active respondents who reported the same – See Figure 73.

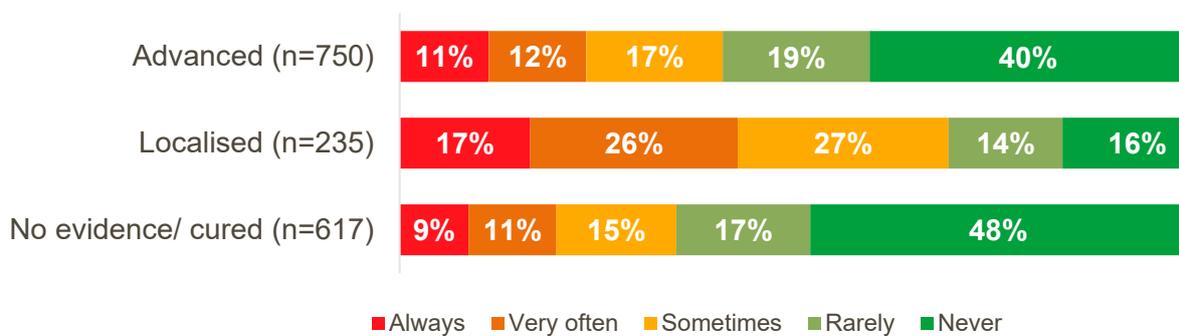
**Figure 73: Q22k – How often have the following impacted your sense of emotional well-being since your diagnosis? – DIFFICULTY NAVIGATING THE HEALTHCARE SYSTEM by Level of physical activity**



### Problems getting health or life insurance coverage

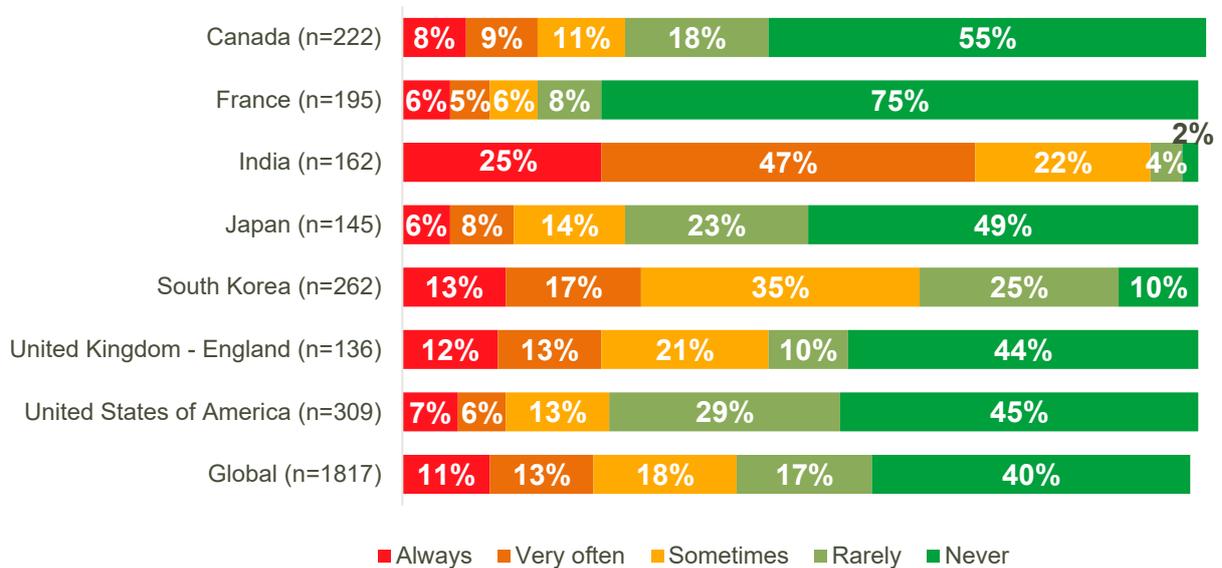
Respondents in the localised stage of the disease were nearly twice as likely to state they are always or very often concerned with getting health or life insurance (43%, n=101) than respondents at the advanced stage (24%, n=178). Localised respondents were also more than twice as likely to state this was a concern than respondents with no current evidence of kidney cancer/growth (20%, n=123) – see Figure 74.

**Figure 74: Q22l – How often have the following impacted your sense of emotional well-being since your diagnosis? – PROBLEMS GETTING HEALTH OR LIFE INSURANCE by Stage of disease today**



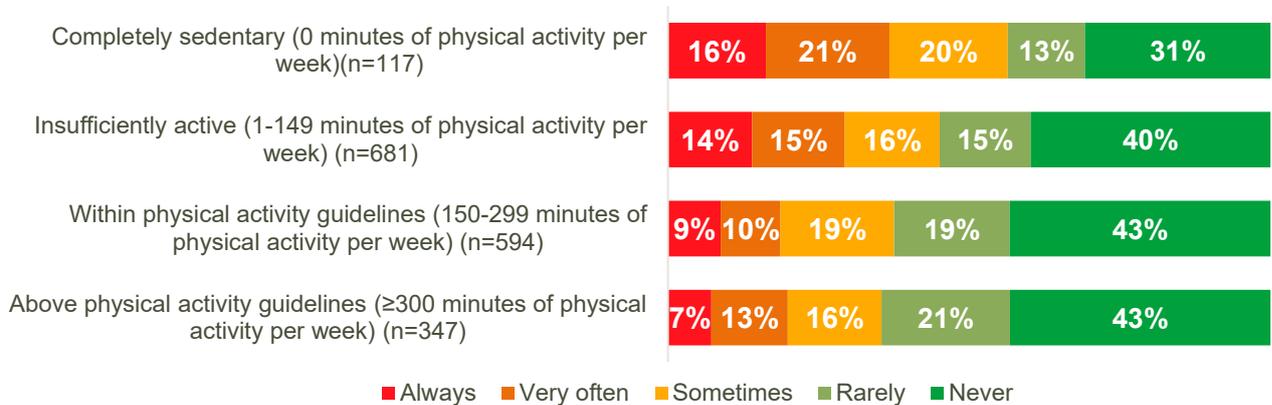
Problems getting health or life insurance was a smaller concern globally with 4 in 10 (40%, n=732) reporting that this was never a concern. Again, residents of India and South Korea report a notably different experience – as displayed in Figure 75. 1 in 4 (25%, n=41) reported that this was always a concern in India and only 2% (n=3) said that it was never an emotional issue. In South Korea, only 10% (n=26) of respondents indicated that problems getting health or life insurance was never a concern.

Figure 75: Q22I – How often have the following impacted your sense of emotional well-being since your diagnosis? – PROBLEMS GETTING HEALTH OR LIFE INSURANCE by Country of residence



37% (n=43) of those respondents that indicated that they are completely sedentary indicated that they always/very often had concerns about problems getting health or life insurance. This is notably higher than those that exercised within the recommended physical guidelines (19%, n=111).

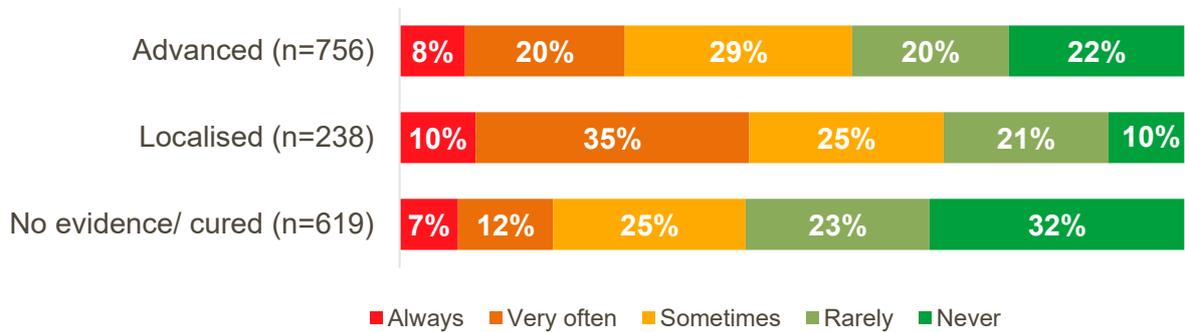
Figure 76: Q22I – How often have the following impacted your sense of emotional well-being since your diagnosis? – PROBLEMS GETTING HEALTH OR LIFE INSURANCE by Level of physical activity



### Concerns about body image/changes in physical appearance

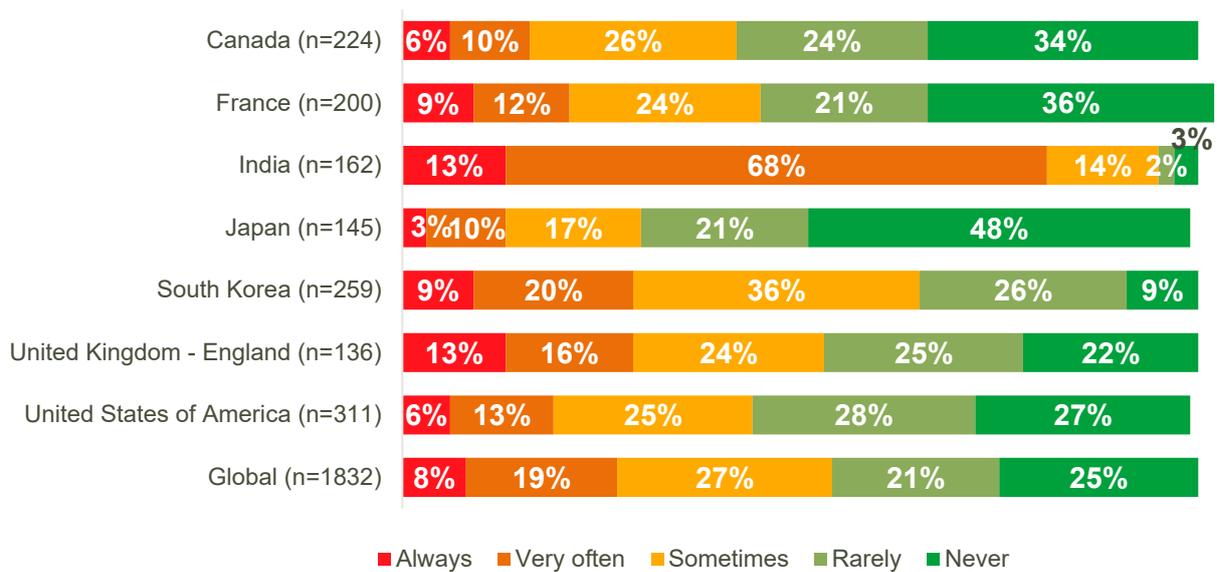
Respondents who currently have no evidence of kidney cancer/growth (32%, n=201) were most likely to state they have never been concerned about body image/changes in physical experience since their diagnosis – see Figure 77. This is considerably higher than reported by respondents at the advanced stage, where 22% (n=169) stated this had never been a concern and at the localised stage, where only 10% (n=23) stated they had never experienced this concern since their diagnosis.

Figure 77: Q22m – How often have the following impacted your sense of emotional well-being since your diagnosis? – CONCERNS ABOUT BODY IMAGE/CHANGES IN PHYSICAL APPEARANCE INSURANCE by Stage of disease today



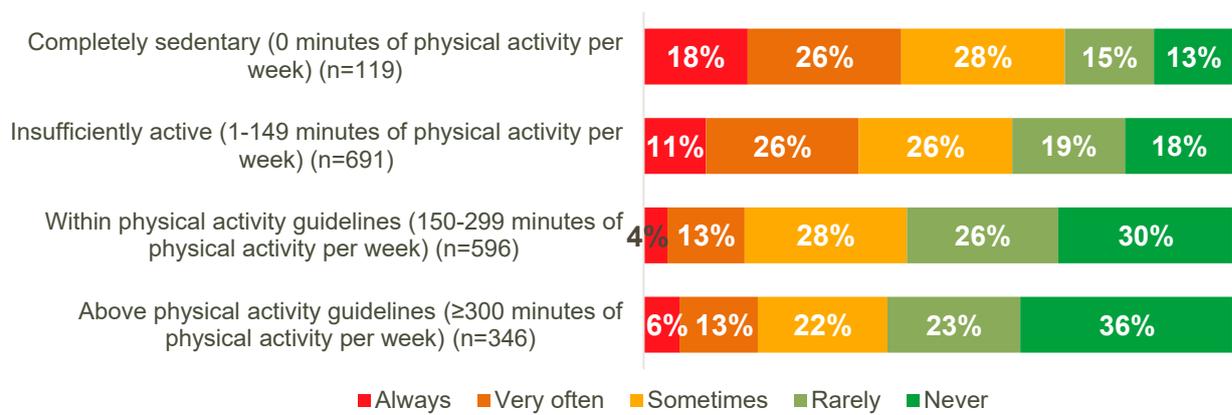
Reported concerns about body image/changes in physical appearance were unusually low in Japan with 48% (n=70) of respondents reporting that they never have this concern. Whereas the opposite is true for respondents in India where 81% (n=131) said that they always/very often had this worry, and only 6% (n=9) reported that it was rarely/never a concern. See Figure 78 for full details.

Figure 78: Q22m – 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 who exercised within physical activity guidelines (30%, n=177) and above physical activity guidelines (36%, n=125) were more than twice as likely to report never experiencing concerns about body images and changes in physical appearance than respondents who reported being completely sedentary (13%, n=16) – See Figure 79.

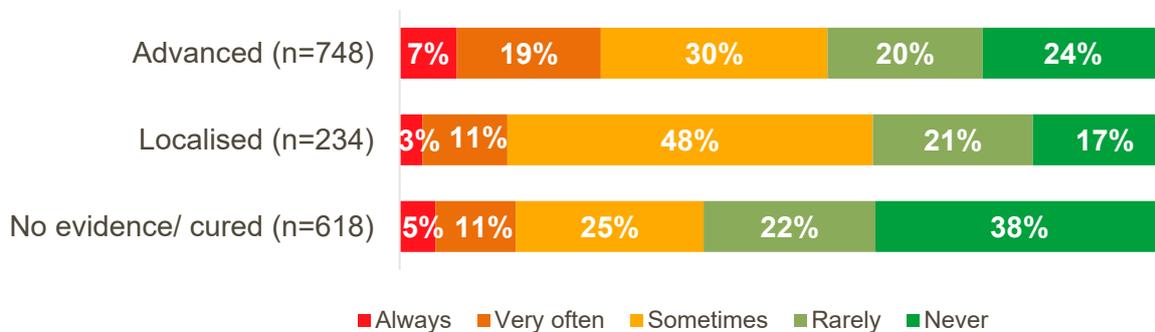
**Figure 79: Q22m – How often have the following impacted your sense of emotional well-being since your diagnosis? – CONCERNS ABOUT BODY IMAGE/CHANGES IN PHYSICAL APPEARANCE by Level of physical activity**



### Sexuality

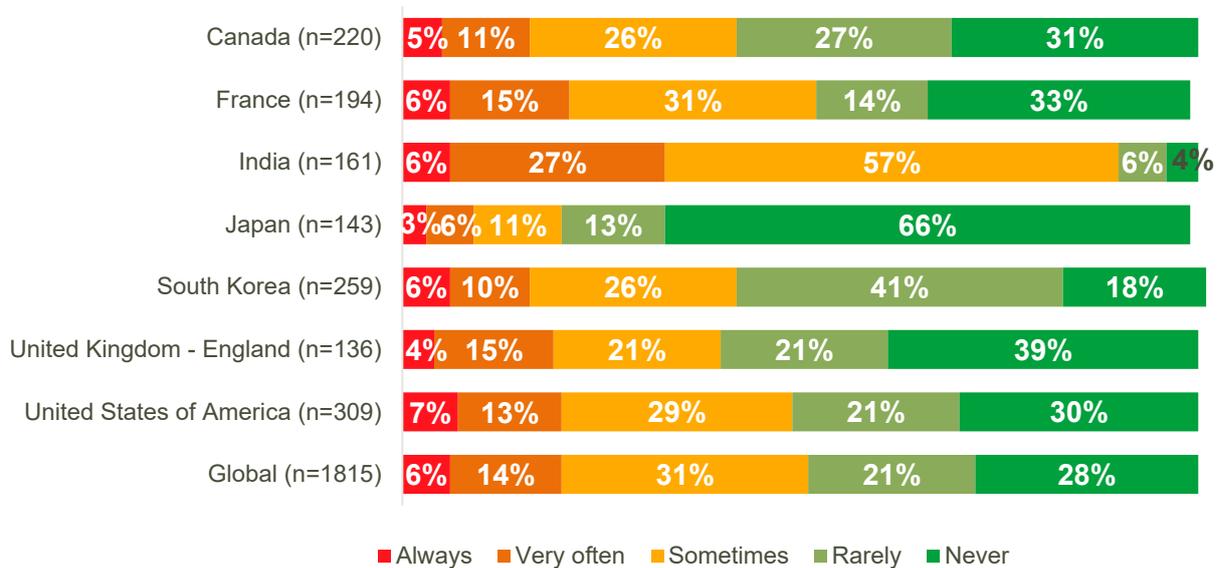
Figure 80 indicates that more than 1 in 4 respondents in the advanced group (26%, n=197) reported sexuality being an emotional concern they always or very often experience since their diagnosis. This is considerably higher than reported for respondents at the localised stage (14%, n=33) and no evidence stage (15%, n=94).

**Figure 80: Q22n – How often have the following impacted your sense of emotional well-being since your diagnosis? – SEXUALITY by Stage of disease today**



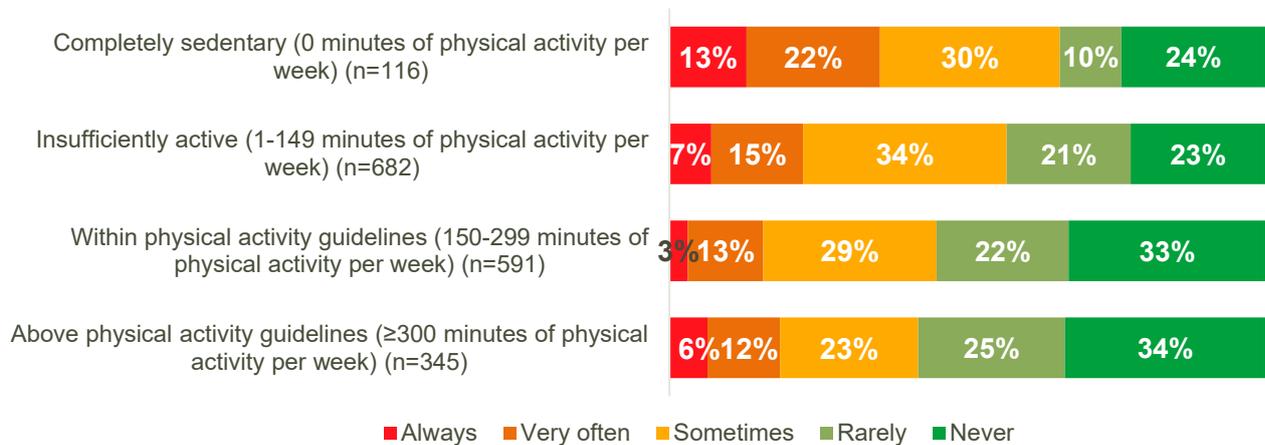
Similarly, to the results for Figure 78, Figure 81 shows that a notably higher percentage of respondents in Japan (66%, n=95) said that sexuality was never an emotional concern relative to other countries. In contrast, only 4% (n=6) of residents from India said this was never a concern.

Figure 81: Q22n – How often have the following impacted your sense of emotional well-being since your diagnosis? – SEXUALITY by Country of residence



Respondents who reported being completely sedentary (13%, n=15) were more than twice as likely to report always have concerns over their sexuality than non-sedentary respondents – See Figure 81.

Figure 82: Q22n – How often have the following impacted your sense of emotional well-being since your diagnosis? – SEXUALITY by Level of physical activity



### Sources of support

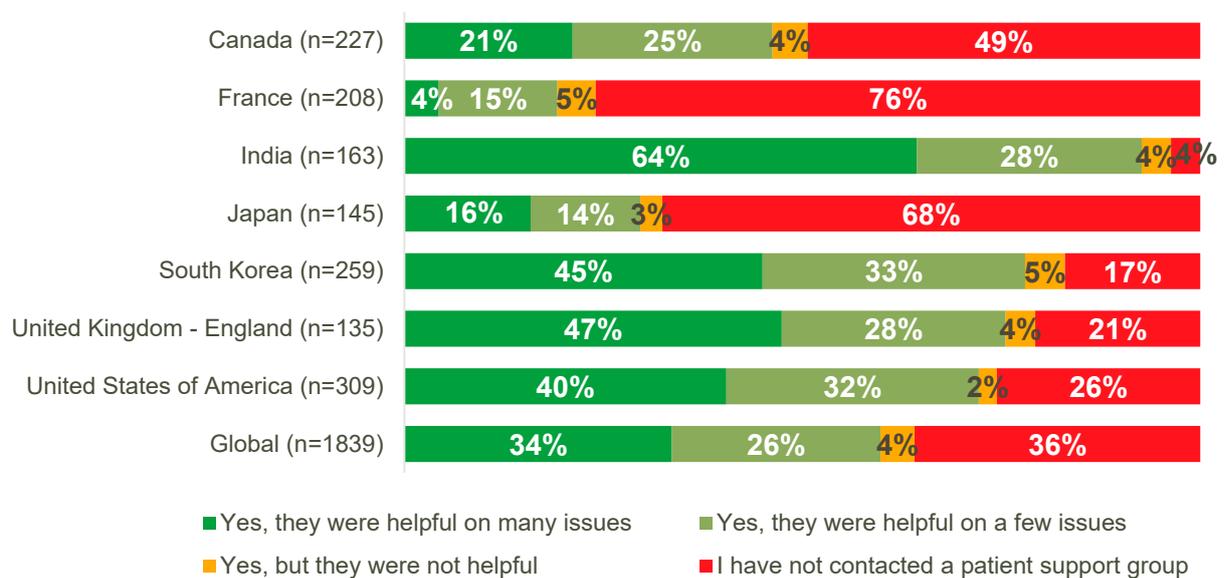
Even though many respondents indicated they had either physical and/or emotional concerns, only 52% (n=886) reported having spoken to a doctor or other healthcare professional.

Those in the younger age category (18-29) reported that they were less likely to have sought support from a professional. Only 41% of respondents (n=14) indicated that they had compared to 54% of respondents in both the 46-65 (n=544) and 66-80 (n=190) age categories.

Professional advice is not the only source of support. 64% (n=1179) of respondents globally indicated that they had spoken to a patient support group, although this likely reflects an inherent bias attributable to the survey distribution and promotion through patient organisations. These seem to be more popular with the younger demographics. 69% (n=24) of respondents aged 18-29 indicated that they had sought support in this manner compared to 56% (n=18) who were aged over 80.

Respondents from different countries reported varying levels of seeking support from patient support groups, as outlined in Figure 83.

**Figure 83: Q25 – Have you ever used a patient support group (either in person or online) to help you with your kidney cancer / growth? by Country of residence**



Respondents based in France were most likely to report that they had not contacted a patient support group (76%, n=158), followed by respondents residing in Japan (68%, n=98).

In contrast, respondents who resided in India were the most likely to report that they had contacted a patient support group (96%, n=157). Of those residents of India that did contact a patient support group, 64%, (n=105) reported that they were helpful on many issues.

### Patient health engagement

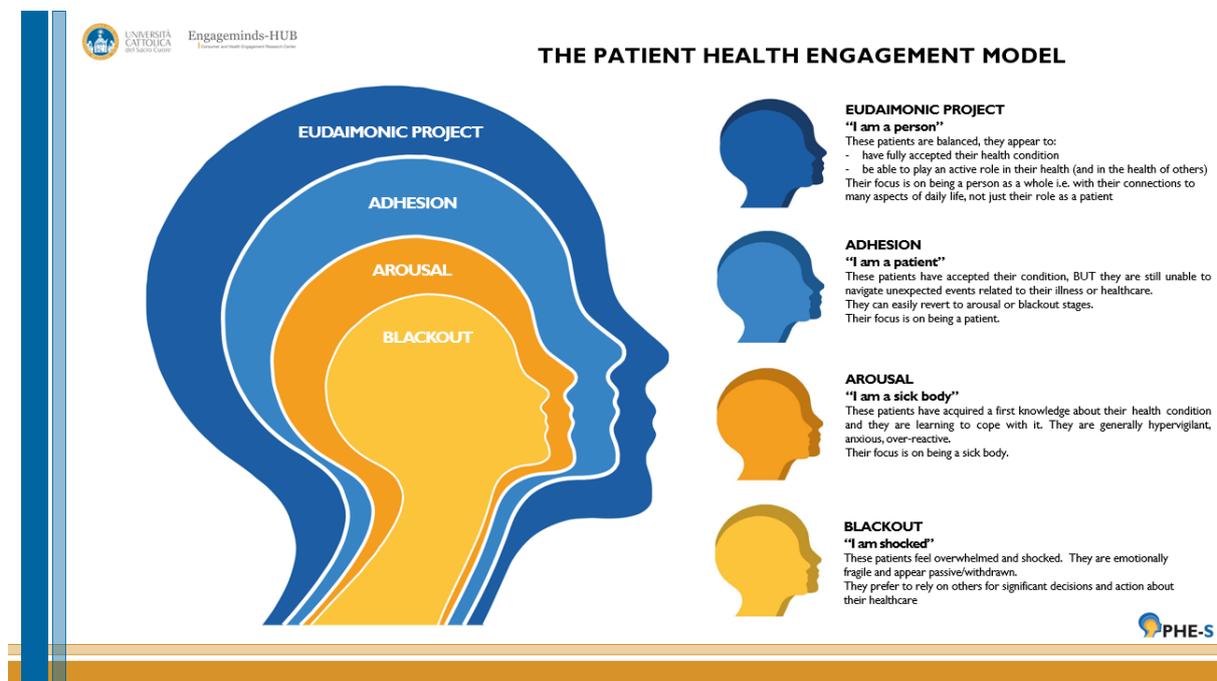
A key factor for improving healthcare delivery is overall patient engagement. To measure the psychological experience of patients' engagement in their own care a new addition for the 2020 survey was the Patient Health Engagement Scale<sup>9</sup> (PHE-S) a validated instrument

<sup>9</sup> Graffigna, G., Barello, S., Bonanomi, A., & Lozza, E. (2015). Measuring patient engagement: development and psychometric properties of the Patient Health Engagement (PHE) Scale. *Frontiers in psychology*, 6, 274.

developed from the Patient Health Engagement Model (PHE-model) by *Università Cattolica del Sacro Cuore*, in Italy.

The PHE-S is a 5 item, 7-point scale that can be used to define the patient’s engagement position relating to their personal “level of processing and acceptance of their disease” (*Graffigna et al. 2015*). Upon completion of the tool, all patients are categorised as being in one of four states in the Patient Health Engagement (PHE) Model ranging from what Prof. Graffigna defines as “Blackout” to “Eudaimonic project” as outlined in Figure 84. She defines “Blackout” as being where the patient appears to be unable to engage with their illness and healthcare and must rely on others for guidance and decision making (i.e. they are passive recipients of care) and “Eudaimonic project” as being where the patient has fully accepted their condition and has a positive approach to/are partners with healthcare professionals in their healthcare, (i.e. they have meaning and purpose).

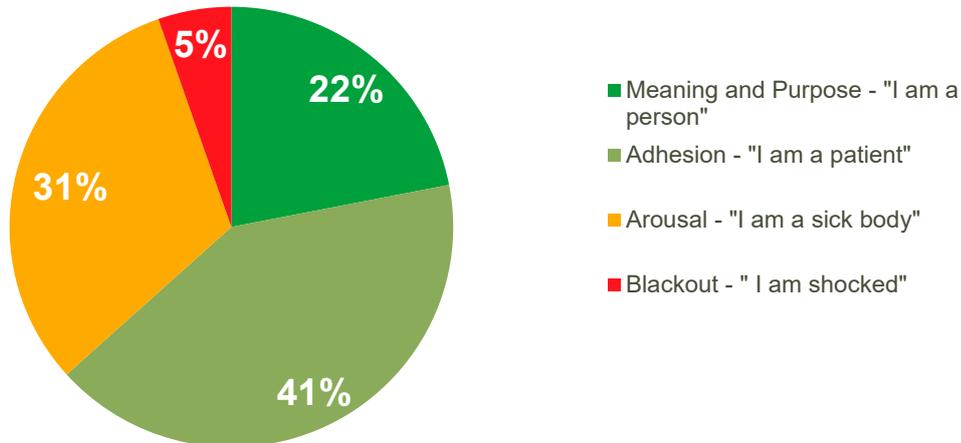
**Figure 84: The four states of the Patient Health Engagement Model**



For clarity of meaning, throughout this report we refer to the ‘Eudaimonic Project’ stage as ‘Meaning and Purpose’. In addition, results are presented in the four developmental stages as outlined in the Patient Health Engagement Model. To view the full tool and percentage split of all global respondents please see the Frequency Tables in Appendix 2.

Of all the respondents globally, only 5% (n=98) can be categorised as being in the ‘Blackout – I am shocked’ state. The largest percentage of patients can be defined as being in the ‘Adhesion – I am a patient’ state (41%, n=760). See Figure 85 for the full profile. However, there were notable demographic differences.

Figure 85: PHE-S: Patient state – Global profile (n=1837)

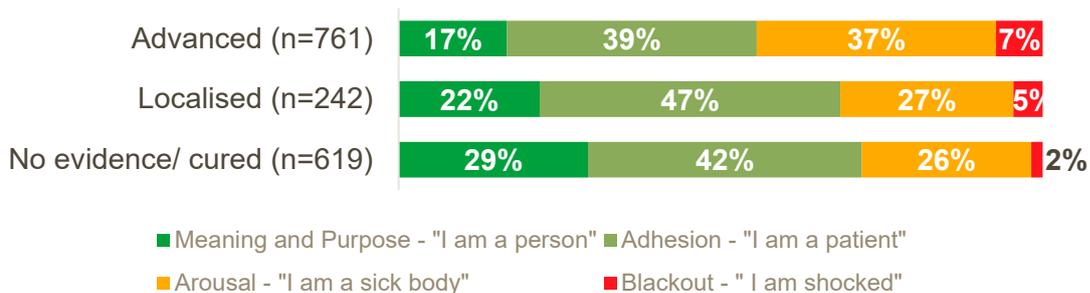


### Patient state by stage of disease

As outlined in Figure 86, 29% (n=182) of respondents who reported that they currently had no evidence of the disease / had been cured indicated (via their responses to the PHE-S scale) that they were in the ‘Meaning and Purpose – I am a person’ state, with a further 42% (n=263) of the respondents indicating that they were in the ‘Adhesion – I am a patient’ state.

In comparison, only 17% (n=128) of those in advanced stages of the disease indicated via their PHE-S responses that they were in the ‘Meaning and Purpose – I am a person’ state. 7% (n=55) were classified as being in the ‘Blackout – I am shocked’ state and 37% (n=283) in the ‘Arousal – I am a sick body’

Figure 86: PHE-S: Patient state – Stage of disease today profile

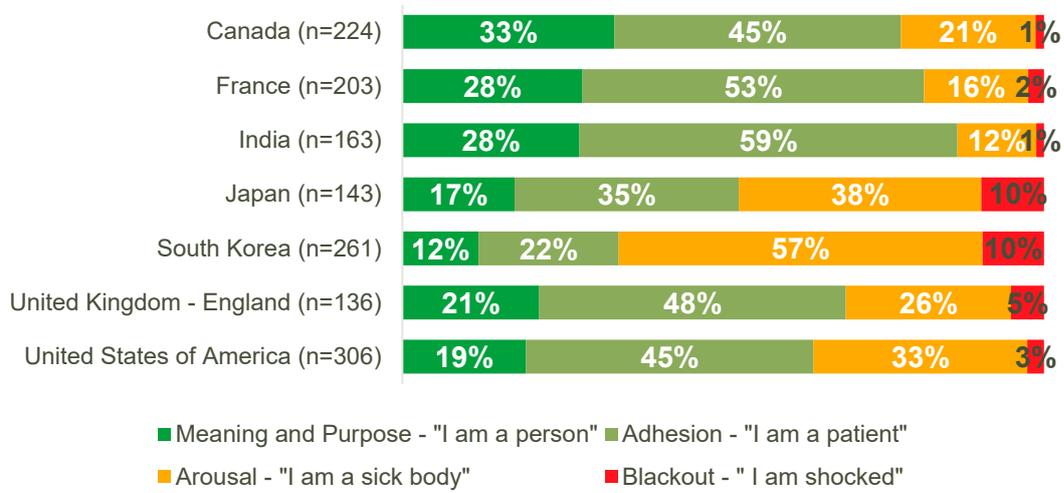


### Patient state by country variation

The largest proportion of respondents in all countries apart from Japan and South Korea were classified as being in the ‘Adhesion – I am a patient’ state – see Figure 87. However, relative to other countries, a notably larger percentage of respondents from South Korea were classed as being in the ‘Arousal – I am a sick body’ (57%, n=148) state.

Canada is the country with the greatest percentage of respondents that could be classified as being in the ‘Meaning and Purpose – I am a person’ state, (33%, n=74). Closely followed by France (28%, n=57) and India (28%, n=45).

Figure 87: PHE-S: Patient state – Country of residence profile



## Conclusion

This report presents data from the International Kidney Cancer Coalition (IKCC) biennial Global Survey 2020, 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. Some highlights that may potentially be actionable:

- Diagnosis – The 2020 survey results broadly support the benchmark 2018 survey data and underscore the fact that substantial numbers of patients do not understand their diagnosis, especially tumour subtype. Understanding the tumour subtype has important implications for treatment decision-making.
- Treatment – Understanding treatment options and shared decision making remain problematic, and barriers to care still exist.
- Biopsy practice – Interestingly, only 3% of patients indicated that they were unwilling to undergo a biopsy if offered. The survey captured experience and willingness to repeat in the future.
- Clinical trials – Awareness and overall experience provided similar data to the benchmark data of 2018, showing robust interest in trial participation from the patient perspective, yet trial participation was not offered by the clinical team.
- Physical activity varied greatly between countries, despite its role in treatment and survivorship.
- Patient health engagement – and how to support patients to make sense of their health status and empower themselves.
- Quality of life and overall health status of respondents presented a substantial emotional wellbeing and psychosocial burden. Sources of support – access and experience- varied between countries.

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

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

## Acknowledgements

This report was prepared by the Picker Institute Europe on behalf of the International Kidney Cancer Coalition.

We would like to thank all members of the Global Patient Survey Steering Committee and affiliate organisations for their support and collaboration on this project. The Global Patient Survey Steering Committee 2020 included:

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- Karin Kastrati, Das Lebenshaus, Weikersheim, Germany
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Most importantly, we would like to thank the patients and caregivers who took the time to complete the 2020 survey. This report, and the work of the IKCC and our global affiliate organisations in response to this feedback, is dedicated to you all with our sincere appreciation.

## Appendices

- 1 – List of figures and tables
- 2 – Global Report Frequency Tables
- 3 – 2020 International Kidney Cancer Coalition Questionnaire

### **The following supplementary reports are also available:**

- International Kidney Cancer Coalition Survey 2020 – Local

*Country-specific reports where respondent numbers are greater or equal to 100. These include:*

Canada

South Korea

France

United Kingdom – England

India

United States of America

Japan

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### About the respondents

#### About respondent 2,003 Responses

Q1 - Please describe your experience with kidney cancer and/or kidney growths	Count	Percent
I have been diagnosed with kidney cancer or a kidney growth	1,586	79%
I am a carer or caregiver to someone who has been diagnosed with kidney cancer or a kidney growth	342	17%
My loved one has died	75	4%
Total	2,003	100%

#### Age 1,991 Responses

Q4 - What is your age now?	Count	Percent
46-65	1,185	60%
66-80	425	21%
30-45	298	15%
18-29	41	2%
80+	35	2%
Under 18	7	0%
Total	1,991	100%

#### Gender 2,000 Responses

Q5 - What is your gender?	Count	Percent
Male	1,077	54%
Female	904	45%
Do not wish to identify	13	1%
I prefer to self describe	6	0%
Total	2,000	100%

## About the respondents

### Sub-type of kidney cancer 1,998 Responses

Q2 - What sub-type of kidney cancer do you have?	Count	Percent
Clear Cell Renal Cell Carcinoma	1,273	64%
Papillary Renal Cell Carcinoma	174	9%
Chromophobe Renal Cell Carcinoma	124	6%
Don't know / Can't remember	115	6%
Other	87	4%
I was not told	59	3%
Unclassified Renal Cell Carcinoma	39	2%
VHL (Von Hippel-Lindau syndrome)	25	1%
Benign growth	24	1%
Transitional Cell Carcinoma (Urothelial Carcinoma)	22	1%
Xp11 Translocation Type	21	1%
Wilms Tumour	16	1%
Renal Sarcoma (NOT Renal Cell Carcinoma with Sarcomatoid Appearance)	8	0%
Renal Medullary Carcinoma	7	0%
Collecting Duct Renal Cell Carcinoma (Bellini Duct)	4	0%
Total	1,998	100%

### Country of residence 1,891 Responses

Q3 - In which country do you currently reside?	Count	Percent
Algeria	1	0%
Andorra	1	0%
Angola	1	0%
Argentina	8	0%
Australia	46	2%
Austria	3	0%
Belgium	2	0%
Brazil	25	1%
Canada	241	13%
Colombia	2	0%
Egypt	1	0%
Finland	5	0%
France	234	12%
Germany	39	2%
Greece	5	0%
India	163	9%
Ireland	8	0%
Italy	28	1%
Japan	156	8%
Malaysia	1	0%
Mexico	1	0%
Netherlands	17	1%
New Zealand	6	0%
Norway	2	0%
Peru	2	0%
Poland	6	0%
Portugal	13	1%
Romania	4	0%
Russian Federation	1	0%
South Africa	3	0%
South Korea	300	16%
Spain	50	3%
Sweden	25	1%
Switzerland	1	0%
Tunisia	1	0%
United Kingdom - England	149	8%
United Kingdom - Northern Ireland	1	0%
United Kingdom - Scotland	11	1%
United Kingdom - Wales	5	0%
United States of America	321	17%
Uruguay	2	0%
Total	1,891	100%

## Diagnosis

### Diagnosis Year 1,997 Responses

Q6 - In what year were you diagnosed?	Count ▲	Percent
2017-2019	796	40%
2014-2016	374	19%
2020-present	284	14%
2011-2013	192	10%
Prior to 2008	190	10%
2008-2010	159	8%
DK / CR	2	0%
<b>Total</b>	<b>1,997</b>	<b>100%</b>

### First correctly diagnosed 1,991 Responses

Q7 - Where was your kidney growth FIRST CORRECTLY DIAGNOSED?	Count ▲	Percent
Community/local/general hospital	802	40%
My family doctor's office	299	15%
Emergency department	258	13%
Major cancer centre by a specialist	174	9%
Other	170	9%
Private clinic	170	9%
Major cancer centre	108	5%
Don't know / Can't remember	10	1%
<b>Total</b>	<b>1,991</b>	<b>100%</b>

### When first diagnosed were you told what subtype? 1,994 Responses

Q8 - WHEN YOU WERE FIRST CORRECTLY DIAGNOSED, were you told what sub-type of kidney cancer or kidney growth you had?	Count ▲	Percent
No	909	46%
Yes	842	42%
Not sure	243	12%
<b>Total</b>	<b>1,994</b>	<b>100%</b>

### When first diagnosed were you told what subtype? - Positive Score 1,751 Responses

Q8+ - WHEN YOU WERE FIRST CORRECTLY DIAGNOSED, were you told what sub-type of kidney cancer or kidney growth you had?	Count ▲	Percent
No	909	52%
Yes	842	48%
<b>Total</b>	<b>1,751</b>	<b>100%</b>

### What stage when first diagnosed? 1,990 Responses

Q9 - At what stage was the kidney tumour when you were FIRST CORRECTLY DIAGNOSED? (PLEASE CHOOSE ALL THAT APPLY)	Count ▲	Percent
Tumour was larger than 4cm (Stage 1B or Stage 2)	669	34%
Tumour was less than 4 cm (Stage 1A)	457	23%
Tumour had spread to other organs (Stage 4)	402	20%
Tumour had spread locally outside (Stage 3)	327	16%
I had more than one tumour in the kidney	98	5%
Other	65	3%
Don't know / Can't remember	48	2%
I was not told	41	2%
<b>Total</b>	<b>2,107</b>	<b>106%</b>

## Diagnosis

### How long to correct diagnosis? 1,979 Responses

Q10 - How long was it from the time you first thought something might be wrong with you to being CORRECTLY diagnosed?	Count	Percent
Less than 1 month	812	41%
1 - 3 months	566	29%
3 - 6 months	197	10%
More than 12 months	146	7%
6 months - 12 months	130	7%
DK/ CR	128	6%
Total	1,979	100%

### How long to correct diagnosis? - Positive Score 1,851 Responses

Q10+ - How long was it from the time you first thought something might be wrong with you to being CORRECTLY diagnosed?	Count	Percent
Less than 1 month	812	44%
1 - 3 months	566	31%
3 - 6 months	197	11%
More than 12 months	146	8%
6 months - 12 months	130	7%
Total	1,851	100%

### Explanation at diagnosis - Stage of cancer 1,976 Responses

Q11a - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Stage of cancer	Count	Percent
Yes, completely	823	42%
Yes, to some extent	753	38%
No, this was not explained	337	17%
I did not need an explanation	36	2%
Don't know / can't remember	27	1%
Total	1,976	100%

### Explanation at diagnosis - Stage of cancer - Positive Score 1,913 Responses

Q11a+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Stage of cancer	Count	Percent
Yes, completely	823	43%
Yes, to some extent	753	39%
No, this was not explained	337	18%
Total	1,913	100%

### Explanation at diagnosis - Subtype of cancer 1,857 Responses

Q11b - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Subtype of cancer	Count	Percent
Yes, to some extent	639	34%
No, this was not explained	587	32%
Yes, completely	507	27%
Don't know / can't remember	87	5%
I did not need an explanation	37	2%
Total	1,857	100%

### Explanation at diagnosis - Subtype of cancer - Positive Score 1,733 Responses

Q11b+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Subtype of cancer	Count	Percent
Yes, to some extent	639	37%
No, this was not explained	587	34%
Yes, completely	507	29%
Total	1,733	100%

## Diagnosis

### Explanation at diagnosis - Treatment options 1,868 Responses

Q11c - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment options	Count	Percent
Yes, completely	870	47%
Yes, to some extent	733	39%
No, this was not explained	228	12%
I did not need an explanation	25	1%
Don't know / can't remember	12	1%
<b>Total</b>	<b>1,868</b>	<b>100%</b>

### Explanation at diagnosis - Treatment options - Positive Score 1,831 Responses

Q11c+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment options	Count	Percent
Yes, completely	870	48%
Yes, to some extent	733	40%
No, this was not explained	228	12%
<b>Total</b>	<b>1,831</b>	<b>100%</b>

### Explanation at diagnosis - Treatment recommendations 1,842 Responses

Q11d - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment recommendations	Count	Percent
Yes, completely	856	46%
Yes, to some extent	713	39%
No, this was not explained	222	12%
I did not need an explanation	37	2%
Don't know / can't remember	14	1%
<b>Total</b>	<b>1,842</b>	<b>100%</b>

### Explanation at diagnosis - Treatment recommendations - Positive Score 1,791 Responses

Q11d+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment recommendations	Count	Percent
Yes, completely	856	48%
Yes, to some extent	713	40%
No, this was not explained	222	12%
<b>Total</b>	<b>1,791</b>	<b>100%</b>

### Explanation at diagnosis - Risk of recurrence 1,872 Responses

Q11e - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Risk of recurrence	Count	Percent
Yes, to some extent	707	38%
No, this was not explained	550	29%
Yes, completely	504	27%
I did not need an explanation	65	3%
Don't know / can't remember	46	2%
<b>Total</b>	<b>1,872</b>	<b>100%</b>

### Explanation at diagnosis - Risk of recurrence - Positive Score 1,761 Responses

Q11e+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Risk of recurrence	Count	Percent
Yes, to some extent	707	40%
No, this was not explained	550	31%
Yes, completely	504	29%
<b>Total</b>	<b>1,761</b>	<b>100%</b>

## Diagnosis

### Explanation at diagnosis - Likelihood of surviving beyond 5 yrs 1,869 Responses

Q11f - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Likelihood of surviving beyond 5 yrs	Count ▲	Percent
No, this was not explained	720	39%
Yes, completely	506	27%
Yes, to some extent	501	27%
I did not need an explanation	89	5%
Don't know / can't remember	53	3%
<b>Total</b>	<b>1,869</b>	<b>100%</b>

### Explanation at diagnosis - Likelihood of surviving beyond 5 yrs - Positive Score 1,727 Responses

Q11f+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Likelihood of surviving beyond 5 yrs	Count ▲	Percent
No, this was not explained	720	42%
Yes, completely	506	29%
Yes, to some extent	501	29%
<b>Total</b>	<b>1,727</b>	<b>100%</b>

### Second opinion 1,931 Responses

Q12 - Did you ever seek a second opinion with a kidney cancer expert?	Count ▲	Percent
No	982	51%
Yes	733	38%
Never considered it	141	7%
Not available to me	75	4%
<b>Total</b>	<b>1,931</b>	<b>100%</b>

## Developing a treatment plan

### Involvement in treatment plan 1,970 Responses

Q13 - Were you involved as much as you wanted to be in decisions about your treatment plan?	Count	Percent
Yes, definitely	988	50%
Yes, to some extent	664	34%
No	273	14%
I did not want to be involved	24	1%
Don't know / Can't remember	21	1%
<b>Total</b>	<b>1,970</b>	<b>100%</b>

### Involvement in treatment plan - Positive Score 1,925 Responses

Q13+ - Were you involved as much as you wanted to be in decisions about your treatment plan?	Count	Percent
Yes, definitely	988	51%
Yes, to some extent	664	34%
No	273	14%
<b>Total</b>	<b>1,925</b>	<b>100%</b>

### Support in treatment plan decisions 1,970 Responses

Q14 - Who or what else helped you make decisions about your treatment plan? (PLEASE CHOOSE ALL THAT APPLY)	Count	Percent
My partner / spouse	1,097	56%
My family doctor	329	17%
My friends /other family members	318	16%
Online resources	269	14%
It was my decision alone	269	14%
A patient organisation or support group	266	14%
My children	258	13%
My parents	176	9%
Other	163	8%
My personal financial situation	34	2%
Don't know / Can't remember	23	1%
<b>Total</b>	<b>3,202</b>	<b>163%</b>

### Barriers to treatment 1,923 Responses

Q15 - Which barriers (if any) have you experienced in receiving treatment for your kidney cancer or kidney growth? (PLEASE CHOOSE ALL THAT APPLY)	Count	Percent
I experienced no barriers	839	44%
Cost of treatment	412	21%
Wait time to treatment was an issue for me	346	18%
No access to up-to-date treat. or equipment	260	14%
Difficulty managing carer role while in treat.	242	13%
No access to treatment centre / travel	229	12%
No speciality doctor locally	218	11%
Fear of discrimination if knew about disease	173	9%
Lack of personal support	167	9%
Other barrier not mentioned above	141	7%
No available treatments	81	4%
Language/inability to understand treatment	68	4%
<b>Total</b>	<b>3,176</b>	<b>165%</b>

### Your care and treatment & your care today

#### Stage of kidney cancer or kidney growth TODAY 1,913 Responses

Q16 - Which of the following best describes your stage of kidney cancer or kidney growth TODAY?	Count ▲	Percent
Kidney cancer / growth has spread to other organs or distant sites (Stage 4)	690	36%
I currently have no evidence of disease	535	28%
Kidney cancer / growth is still only within the kidney (Stage 1 or Stage 2)	250	13%
Other (Please specify)	184	10%
I was told that I am cured	114	6%
Kidney cancer / growth is still locally advanced (Stage 3)	97	5%
Don't know / Can't remember	43	2%
<b>Total</b>	<b>1,913</b>	<b>100%</b>

#### Understanding of care/treatment - Surgical options 1,884 Responses

Q18a - I understand surgical options	Count ▲	Percent
Agree	843	45%
Strongly agree	794	42%
Neither agree nor disagree	151	8%
N/A	57	3%
Disagree	29	2%
Strongly disagree	10	1%
<b>Total</b>	<b>1,884</b>	<b>100%</b>

#### Understanding of care/treatment - Immunotherapy options 1,829 Responses

Q18b - I understand immunotherapy options	Count ▲	Percent
Agree	631	34%
Strongly agree	448	24%
Neither agree nor disagree	312	17%
N/A	259	14%
Disagree	142	8%
Strongly disagree	37	2%
<b>Total</b>	<b>1,829</b>	<b>100%</b>

#### Treatment TODAY 1,901 Responses

Q17 - Where are you CURRENTLY being treated or followed?	Count ▲	Percent
At a major cancer centre	910	48%
At a community/ local/ general hospital	627	33%
Other	135	7%
At a private clinic	126	7%
Not currently treated or followed anywhere	103	5%
<b>Total</b>	<b>1,901</b>	<b>100%</b>

#### Understanding of care/treatment - Surgical options - Positive Score 1,827 Responses

Q18a+ - I understand surgical options	Count ▲	Percent
Agree	843	46%
Strongly agree	794	43%
Neither agree nor disagree	151	8%
Disagree	29	2%
Strongly disagree	10	1%
<b>Total</b>	<b>1,827</b>	<b>100%</b>

#### Understanding of care/treatment - Immunotherapy options - Positive Score 1,570 Responses

Q18b+ - I understand immunotherapy options	Count ▲	Percent
Agree	631	40%
Strongly agree	448	29%
Neither agree nor disagree	312	20%
Disagree	142	9%
Strongly disagree	37	2%
<b>Total</b>	<b>1,570</b>	<b>100%</b>

### Your care and treatment & your care today

#### Understanding of care/treatment - Targeted therapy options 1,845 Responses

Q18c - I understand targeted therapy options	Count ▲	Percent
Agree	693	38%
Strongly agree	447	24%
Neither agree nor disagree	281	15%
N/A	249	13%
Disagree	135	7%
Strongly disagree	40	2%
Total	1,845	100%

#### Understanding of care/treatment - Targeted therapy options - Positive Score 1,596 Responses

Q18c+ -I understand targeted therapy options	Count ▲	Percent
Agree	693	43%
Strongly agree	447	28%
Neither agree nor disagree	281	18%
Disagree	135	8%
Strongly disagree	40	3%
Total	1,596	100%

#### Understanding of care/treatment - Radiation therapy options 1,817 Responses

Q18d - I understand radiation therapy options	Count ▲	Percent
Agree	569	31%
Strongly agree	431	24%
Neither agree nor disagree	325	18%
N/A	320	18%
Disagree	131	7%
Strongly disagree	41	2%
Total	1,817	100%

#### Understanding of care/treatment - Radiation therapy options - Positive Score 1,497 Responses

Q18d+ - I understand radiation therapy options	Count ▲	Percent
Agree	569	38%
Strongly agree	431	29%
Neither agree nor disagree	325	22%
Disagree	131	9%
Strongly disagree	41	3%
Total	1,497	100%

#### Understanding of care/treatment - Ablative therapy options 1,820 Responses

Q18e - I understand ablative therapy options	Count ▲	Percent
Agree	529	29%
Neither agree nor disagree	393	22%
Strongly agree	328	18%
N/A	277	15%
Disagree	221	12%
Strongly disagree	72	4%
Total	1,820	100%

#### Understanding of care/treatment - Ablative therapy options - Positive Score 1,543 Responses

Q18e+ - I understand ablative therapy options	Count ▲	Percent
Agree	529	34%
Neither agree nor disagree	393	25%
Strongly agree	328	21%
Disagree	221	14%
Strongly disagree	72	5%
Total	1,543	100%

## Your care and treatment & your care today

Understanding of care/treatment - Palliative 1,816 Responses

Q18f - I understand palliative care	Count ▲	Percent
Agree	657	36%
Neither agree nor disagree	344	19%
Strongly agree	328	18%
N/A	296	16%
Disagree	155	9%
Strongly disagree	36	2%
Total	1,816	100%

Understanding of care/treatment - Palliative - Positive Score 1,520 Responses

Q18f+ - I understand palliative care	Count ▲	Percent
Agree	657	43%
Neither agree nor disagree	344	23%
Strongly agree	328	22%
Disagree	155	10%
Strongly disagree	36	2%
Total	1,520	100%

Understanding of care/treatment - Active Surveillance 1,832 Responses

Q18g - I understand active surveillance	Count ▲	Percent
Agree	745	41%
Strongly agree	527	29%
Neither agree nor disagree	253	14%
N/A	136	7%
Disagree	136	7%
Strongly disagree	35	2%
Total	1,832	100%

Understanding of care/treatment - Active Surveillance - Positive Score 1,696 Responses

Q18g+ - I understand active surveillance	Count ▲	Percent
Agree	745	44%
Strongly agree	527	31%
Neither agree nor disagree	253	15%
Disagree	136	8%
Strongly disagree	35	2%
Total	1,696	100%

Understanding of care/treatment - Role of nutrition/lifestyle 1,831 Responses

Q18h - I understand the role of nutrition/lifestyle on my wellbeing	Count ▲	Percent
Agree	834	46%
Strongly agree	559	31%
Neither agree nor disagree	275	15%
Disagree	93	5%
N/A	50	3%
Strongly disagree	20	1%
Total	1,831	100%

Understanding of care/treatment - Role of nutrition/lifestyle - Positive Score 1,781 Responses

Q18h+ - I understand the role of nutrition/lifestyle on my wellbeing	Count ▲	Percent
Agree	834	47%
Strongly agree	559	31%
Neither agree nor disagree	275	15%
Disagree	93	5%
Strongly disagree	20	1%
Total	1,781	100%

### Your care and treatment & your care today

#### Understanding of care/treatment - Complementary therapies 1,824

Responses

Q18i - I understand complementary therapies (e.g. meditation, etc.)	Count ▲	Percent
Agree	584	32%
Neither agree nor disagree	434	24%
Strongly agree	365	20%
Disagree	210	12%
N/A	169	9%
Strongly disagree	62	3%
Total	1,824	100%

#### Understanding of care/treatment - Complementary therapies - Positive Score 1,655 Responses

Q18i+ - I understand complementary therapies (e.g. meditation, etc.)	Count ▲	Percent
Agree	584	35%
Neither agree nor disagree	434	26%
Strongly agree	365	22%
Disagree	210	13%
Strongly disagree	62	4%
Total	1,655	100%

#### Understanding of care/treatment - Local guidelines for care 1,815 Responses

Q18j - I understand my local guidelines for kidney cancer care	Count ▲	Percent
Agree	700	39%
Strongly agree	381	21%
Neither agree nor disagree	372	20%
Disagree	188	10%
N/A	114	6%
Strongly disagree	60	3%
Total	1,815	100%

#### Understanding of care/treatment - Local guidelines for care - Positive Score 1,701 Responses

Q18j+ - I understand my local guidelines for kidney cancer care	Count ▲	Percent
Agree	700	41%
Strongly agree	381	22%
Neither agree nor disagree	372	22%
Disagree	188	11%
Strongly disagree	60	4%
Total	1,701	100%

#### Understanding of care/treatment - Local guidelines for follow up 1,823

Responses

Q18k - I understand my local guidelines for kidney cancer follow up	Count ▲	Percent
Agree	750	41%
Strongly agree	453	25%
Neither agree nor disagree	322	18%
Disagree	158	9%
N/A	89	5%
Strongly disagree	51	3%
Total	1,823	100%

#### Understanding of care/treatment - Local guidelines for follow up - Positive Score 1,734 Responses

Q18k+ - I understand my local guidelines for kidney cancer follow up	Count ▲	Percent
Agree	750	43%
Strongly agree	453	26%
Neither agree nor disagree	322	19%
Disagree	158	9%
Strongly disagree	51	3%
Total	1,734	100%

### Your care and treatment & your care today

#### Biopsy experience 1,854 Responses

Q19 - Have you ever been offered a biopsy of some part of your body where kidney cancer was thought to be? (PLEASE CHOOSE ALL THAT APPLY)

	Count ^	Percent
No - tissue was looked at after surgery to remove it	664	36%
Yes - I had a biopsy of the kidney growth	550	30%
No - I was never offered a biopsy	314	17%
Yes - I had a biopsy of another part of my body	279	15%
Yes - I was offered a biopsy but I chose not to	47	3%
<b>Total</b>	<b>1,854</b>	<b>100%</b>

#### Biopsy 1,018 Responses

Q20 - Would you be willing to have a biopsy in the future if necessary?

	Count ^	Percent
Yes	474	47%
Maybe	393	39%
No	151	15%
<b>Total</b>	<b>1,018</b>	<b>100%</b>

### Quality of life

#### Physical activity 1,867 Responses

Q21 - I would describe my current level of leisure-time physical activity (defined as physical activity done during free time that lasted at least 10 minutes) as:

Count ▲ Percent

	Count	Percent
Insufficiently active (1-149 minutes of physical activity per week)	705	38%
Within physical activity guidelines (150-299 minutes of physical activity per week)	612	33%
Above physical activity guidelines ( $\geq$ 300 minutes of physical activity per week)	352	19%
Completely sedentary (0 minutes of physical activity per week)	125	7%
Prefer not to answer.	73	4%
<b>Total</b>	<b>1,867</b>	<b>100%</b>

#### Physical activity - Positive Score 1,794 Responses

Q21+ - I would describe my current level of leisure-time physical activity (defined as physical activity done during free time that lasted at least 10 minutes) as:

Count ▲ Percent

	Count	Percent
Insufficiently active (1-149 minutes of physical activity per week)	705	39%
Within physical activity guidelines (150-299 minutes of physical activity per week)	612	34%
Above physical activity guidelines ( $\geq$ 300 minutes of physical activity per week)	352	20%
Completely sedentary (0 minutes of physical activity per week)	125	7%
<b>Total</b>	<b>1,794</b>	<b>100%</b>

#### Emotional well-being - General anxiety 1,858 Responses

Q22a - How often have the following impacted your sense of emotional well-being since your diagnosis?

Count ▲ Percent

	Count	Percent
Sometimes	699	38%
Very often	456	25%
Always	336	18%
Rarely	280	15%
Never	87	5%
<b>Total</b>	<b>1,858</b>	<b>100%</b>

#### Emotional well-being - Disease related anxiety 1,833 Responses

Q22b - How often have the following impacted your sense of emotional well-being since your diagnosis?

Count ▲ Percent

	Count	Percent
Sometimes	684	37%
Very often	561	31%
Always	343	19%
Rarely	194	11%
Never	51	3%
<b>Total</b>	<b>1,833</b>	<b>100%</b>

#### Emotional well-being - Fear of dying 1,838 Responses

Q22c - How often have the following impacted your sense of emotional well-being since your diagnosis?

Count ▲ Percent

	Count	Percent
Sometimes	770	42%
Rarely	371	20%
Very often	351	19%
Always	212	12%
Never	134	7%
<b>Total</b>	<b>1,838</b>	<b>100%</b>

#### Emotional well-being - Fear of cancer/growth coming back 1,825 Responses

Q22d - How often have the following impacted your sense of emotional well-being since your diagnosis?

Count ▲ Percent

	Count	Percent
Sometimes	594	33%
Very often	537	29%
Always	466	26%
Rarely	166	9%
Never	62	3%
<b>Total</b>	<b>1,825</b>	<b>100%</b>

## Quality of life

### Emotional well-being - Depression 1,837 Responses

Q22e - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Sometimes	626	34%
Rarely	441	24%
Very often	309	17%
Never	290	16%
Always	171	9%
Total	1,837	100%

### Emotional well-being - Isolation 1,823 Responses

Q22f - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Sometimes	555	30%
Rarely	429	24%
Never	405	22%
Very often	331	18%
Always	103	6%
Total	1,823	100%

### Emotional well-being - Changes in relationships 1,838 Responses

Q22g - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Sometimes	559	30%
Never	426	23%
Rarely	414	23%
Very often	336	18%
Always	103	6%
Total	1,838	100%

### Emotional well-being - Difficulty in daily living 1,828 Responses

Q22h - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Sometimes	548	30%
Rarely	401	22%
Never	381	21%
Very often	304	17%
Always	194	11%
Total	1,828	100%

### Emotional well-being - Stress related to financial issues 1,834 Responses

Q22i - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	488	27%
Sometimes	455	25%
Rarely	407	22%
Very often	256	14%
Always	228	12%
Total	1,834	100%

### Emotional well-being - Loss/reduction in employment 1,816 Responses

Q22j - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	703	39%
Sometimes	335	18%
Rarely	312	17%
Always	244	13%
Very often	222	12%
Total	1,816	100%

## Quality of life

### Emotional well-being - Difficulty navigating the healthcare system 1,834

Responses

Q22k - How often have the following impacted your sense of emotional well-being since your diagnosis?

Count ▲ Percent

	Count ▲	Percent
Sometimes	493	27%
Rarely	460	25%
Never	444	24%
Very often	286	16%
Always	151	8%
Total	1,834	100%

### Emotional well-being - Problems getting health or life insurance coverage

1,817 Responses

Q22l - How often have the following impacted your sense of emotional well-being since your diagnosis?

Count ▲ Percent

	Count ▲	Percent
Never	732	40%
Sometimes	333	18%
Rarely	317	17%
Very often	239	13%
Always	196	11%
Total	1,817	100%

### Emotional well-being - Concerns about body image/physical appearance

1,832 Responses

Q22m - How often have the following impacted your sense of emotional well-being since your diagnosis?

Count ▲ Percent

	Count ▲	Percent
Sometimes	496	27%
Never	454	25%
Rarely	389	21%
Very often	344	19%
Always	149	8%
Total	1,832	100%

### Emotional well-being - Sexuality 1,815 Responses

1,815 Responses

Q22n - How often have the following impacted your sense of emotional well-being since your diagnosis?

Count ▲ Percent

	Count ▲	Percent
Sometimes	556	31%
Never	511	28%
Rarely	381	21%
Very often	259	14%
Always	108	6%
Total	1,815	100%

## Quality of life

### Seeking support from medical professional 1,790 Responses

Q24 - Have you ever talked to your doctor or to any other healthcare professional about any of these concerns?	Count ▲	Percent
Yes	886	49%
No	813	45%
Don't know / Can't remember	91	5%
<b>Total</b>	<b>1,790</b>	<b>100%</b>

### Seeking support from medical professional - Positive Score 1,699 Responses

Q24+ - Have you ever talked to your doctor or to any other healthcare professional about any of these concerns?	Count ▲	Percent
Yes	886	52%
No	813	48%
<b>Total</b>	<b>1,699</b>	<b>100%</b>

### Seeking support from PSG 1,881 Responses

Q25 - Have you ever used a patient support group (either in person or online) to help you with your kidney cancer / growth?	Count ▲	Percent
I have not contacted a patient support group	660	35%
Yes, they were helpful on many issues	618	33%
Yes, they were helpful on a few issues	482	26%
Yes, but they were not helpful	79	4%
Don't know / Can't remember	42	2%
<b>Total</b>	<b>1,881</b>	<b>100%</b>

### Seeking support from PSG - Positive Score 1,839 Responses

Q25+ - Have you ever used a patient support group (either in person or online) to help you with your kidney cancer / growth?	Count ▲	Percent
I have not contacted a patient support group	660	36%
Yes, they were helpful on many issues	618	34%
Yes, they were helpful on a few issues	482	26%
Yes, but they were not helpful	79	4%
<b>Total</b>	<b>1,839</b>	<b>100%</b>

## Cancer clinical trials

### Discussion with whom 1,854 Responses

Q26 - Who, if anyone, has discussed cancer clinical trials with you? (PLEASE CHOOSE ALL THAT APPLY)	Count	Percent
No one	855	46%
Doctor / Nurse	697	38%
Patient organisation or support group	280	15%
Spouse, friend or family	197	11%
Other (Please specify)	70	4%
Don't know / Can't remember	45	2%
<b>Total</b>	<b>2,144</b>	<b>116%</b>

### Invitation to cancer clinical trials 1,874 Responses

Q27 - Have you ever been invited to participate in a cancer clinical trial?	Count	Percent
No	1,170	62%
Yes	549	29%
Don't know / can't remember	115	6%
Don't know of any clinical trials in my country	40	2%
<b>Total</b>	<b>1,874</b>	<b>100%</b>

### Invitation to cancer clinical trials - Positive Score 1,759 Responses

Q27+ - Have you ever been invited to participate in a cancer clinical trial?	Count	Percent
No	1,170	67%
Yes	549	31%
I do not know of any clinical trials in my country	40	2%
<b>Total</b>	<b>1,759</b>	<b>100%</b>

### Actually participated 949 Responses

Q28 - Did you agree to participate in the cancer clinical trial?	Count	Percent
Yes	529	56%
No	323	34%
DK / CR	97	10%
<b>Total</b>	<b>949</b>	<b>100%</b>

### Actually participated - Positive Score 852 Responses

Q28+ - Did you agree to participate in the cancer clinical trial?	Count	Percent
Yes	529	62%
No	323	38%
<b>Total</b>	<b>852</b>	<b>100%</b>

## Cancer clinical trials

### Reasons for participation 520 Responses

Q29 - Why did you agree to participate? (PLEASE CHOOSE ALL THAT APPLY)	Count	Percent
My doctor recommended it	301	58%
I thought it might offer better care	275	53%
I wanted to help kidney cancer research	232	45%
It was my only option for treatment	77	15%
I wanted a specific type of treatment	76	15%
Affordability, financial reasons	67	13%
Other	42	8%
Don't know / Can't remember	5	1%
<b>Total</b>	<b>1,075</b>	<b>207%</b>

### Satisfaction with overall experience of clinical trial 503 Responses

Q30 - How satisfied were you overall with your cancer clinical trial experience?	Count	Percent
Very satisfied	185	37%
Satisfied	153	30%
Neither satisfied nor dissatisfied	125	25%
Dissatisfied	23	5%
Very dissatisfied	17	3%
<b>Total</b>	<b>503</b>	<b>100%</b>

### Potential participation 1,309 Responses

Q31 - If you had been or were invited, how likely is it that you would participate in a cancer clinical trial?	Count	Percent
Likely	455	35%
Very likely	393	30%
Neither likely nor unlikely	330	25%
Unlikely	85	6%
Very unlikely	46	4%
<b>Total</b>	<b>1,309</b>	<b>100%</b>

## Patient Health Engagement scale from the Università Cattolica del Sacro Cuore

Thinking about my health status... 1,815 Responses

Q32 - I feel in blackout - I feel on alert - I am aware - I feel positive	Count	Percent
I am aware	648	36%
I feel on the alert	479	26%
I feel positive	378	21%
I am aware/I feel positive	113	6%
I feel in blackout	99	5%
I feel on the alert/I am aware	62	3%
I feel in blackout/I feel on the alert	36	2%
Total	1,815	100%

Thinking about my health status... 1,788 Responses

Q33 - I feel dazed - I am in alarm - I am conscious - I feel serene	Count	Percent
I am conscious	833	47%
I feel serene	309	17%
I am in alarm	255	14%
I feel dazed	137	8%
I am conscious/I feel serene	127	7%
I am in alarm/I am conscious	87	5%
I feel dazed/I am in alarm	40	2%
Total	1,788	100%

Thinking about my health status... 1,799 Responses

Q34 - I am overwhelmed - I feel anxious - I am used - I perceive coherence	Count	Percent
I feel anxious every time a new symptom arises	537	30%
Despite my illness I perceive coherence and continuity in my life	528	29%
I have got used to my illness condition	365	20%
Anxious every time a new symptom arises/I have got used to my illness condition	117	7%
When I think about my illness I feel overwhelmed by emotions	103	6%
I have got used to my illness condition/Despite my illness I perceive coherence and continuity in my life	102	6%
I feel overwhelmed by emotions/anxious every time a new symptom arises	47	3%
Total	1,799	100%

Thinking about my health status... 1,778 Responses

Q35 - I feel very discouraged - I feel anxious - I feel adjusted - I feel optimistic	Count	Percent
I feel I have adjusted to my illness	506	28%
I am generally optimistic about my future and my health condition	474	27%
I feel anxious when I try to manage my illness	344	19%
I feel very discouraged due to my illness	160	9%
I feel I have adjusted to my illness/I am generally optimistic about my future and my health condition	127	7%
I feel anxious when I try to manage my illness/I feel I have adjusted to my illness	116	7%
I feel very discouraged due to my illness/I feel anxious when I try to manage my illness	51	3%
Total	1,778	100%

### Patient Health Engagement scale from the Università Cattolica del Sacro Cuore

Thinking about my health status... 1,781 Responses

Q36 - I feel totally oppress - I am upset - I have accepted - I have sense	Count	Percent
I can give sense to my life despite my illness condition	513	29%
I am upset when a new symptom arises	480	27%
I feel I have accepted my illness	468	26%
I am upset when a new symptom arises/I feel I have accepted my illness	115	6%
I feel I have accepted my illness/I can give sense to my life despite my illness condition	96	5%
I feel totally oppressed by my illness	66	4%
I feel totally oppressed by my illness/I am upset when a new symptom arises	43	2%
Total	1,781	100%

## Appendix 3: International Kidney Cancer Global Survey 2020 Questionnaire



English (United Kingdom) ▾

# 2020 International Kidney Cancer Coalition Global Survey

Thank you for participating in this survey.

By doing so, you are helping the International Kidney Cancer Coalition (IKCC) and local patient organisations gain a better understanding of the different issues that patients deal with around the world on a day to day basis. With this information, we will be better equipped to advocate for change to help improve the lives of 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!

### **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 to someone 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*

### **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.*

## 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)

## In which country do you currently reside?

## What is your age now?

- Under 18
- 18-29
- 30-45
- 46-65
- 66-80
- 80+

What is your gender?

- Male
- Female
- 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.*

In what year were you diagnosed?

- Prior to 2008
- 2008-2010
- 2011-2013
- 2014-2016
- 2017-2019
- 2020-present
- Don't know / Can't remember

Where was your kidney growth FIRST CORRECTLY  
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)

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

- Yes
- No
- Not sure

At what stage was the kidney tumour when you were FIRST CORRECTLY DIAGNOSED? (PLEASE CHOOSE ALL THAT APPLY)

- I had more than one tumour in the kidney.
- 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)

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

AT THE TIME OF DIAGNOSIS, 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"/>

Did you ever seek a second opinion with a kidney cancer expert?

- Yes
- No
- I have never considered it
- This was not available to me

## **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.*

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

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*

Which barriers (if any) have you experienced in receiving treatment 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.*

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)

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)



Have you ever been offered a biopsy of some part of your body where kidney cancer was thought to be? (PLEASE CHOOSE ALL THAT APPLY)

- Yes - I had a biopsy of the kidney growth
- Yes - I had a biopsy of another part of my body
- Yes - I was offered a biopsy but I chose not to
- No - tissue was looked at after surgery to remove it
- No - I was never offered a biopsy

Would you be willing to have a biopsy in the future if necessary?

- Yes
- No
- Maybe

### **Quality of life**

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

I would describe my current level of leisure-time physical activity (defined as physical activity done during free time that lasted at least 10 minutes) as:

- Completely sedentary (0 minutes of physical activity per week)
- Insufficiently active (1-149 minutes of physical activity per week)
- Within physical activity guidelines (150-299 minutes of physical activity per week)
- Above physical activity guidelines ( $\geq 300$  minutes of physical activity per week)
- Prefer not to answer.

# 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"/>				
Disease-related anxiety	<input type="radio"/>				
Fear of dying	<input type="radio"/>				
Fear of the cancer/growth coming back (recurrence)	<input type="radio"/>				
Depression	<input type="radio"/>				
Isolation	<input type="radio"/>				
Changes in relationships with loved ones, friends or co-workers	<input type="radio"/>				
Difficulty in daily living, on the job or in school	<input type="radio"/>				
Stress related to financial issues	<input type="radio"/>				
Loss/reduction in employment	<input type="radio"/>				
Difficulty navigating the healthcare system	<input type="radio"/>				
Problems getting health or life insurance coverage	<input type="radio"/>				
Concerns about body image/changes in physical appearance	<input type="radio"/>				
Sexuality	<input type="radio"/>				

Is there anything else that has affected your emotional well-

being?

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

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

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

- Yes, they were helpful on many issues
- Yes, they were helpful on a few issues
- Yes, but they were not helpful
- I have not contacted a patient support group
- Don't know / Can't remember

## **Cancer Clinical Trials**

*These questions explore your understanding of cancer clinical trials.*

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

Have you ever been invited to participate in a cancer clinical trial?

- Yes
- No
- Don't know / can't remember
- I do not know of any clinical trials in my country

Did you agree to participate in the cancer clinical trial?

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

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
- Affordability, financial reasons
- Don't know / Can't remember
- Other

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

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

If you had been or 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

*The final section of this questionnaire is the Patient Health*

*Engagement scale from the Università Cattolica del Sacro Cuore. These questions have been designed to help healthcare practitioners and policy makers customise their interventions to engage patients in care management.*

*Please select the most appropriate phrase/words from the options below that form part of an international template.*

*Graffigna, G., Barello, S., Bonanomi, A., & Lozza, E. (2015). Measuring patient engagement: development and psychometric properties of the Patient Health Engagement (PHE) Scale. Frontiers in psychology, 6, 274.*

Thinking about my health status...

I feel in blackout	↔	I feel on the alert	↔	I am aware	↔	I feel positive
<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Thinking about my health status...

I feel dazed	↔	I am in alarm	↔	I am conscious	↔	I feel serene
<input type="radio"/>		<input type="radio"/>				

### Thinking about my health status...

When I think about my illness I feel overwhelmed by emotions



I feel anxious every time a new symptom arises



I have got used to my illness condition



Despite my illness I perceive coherence and continuity in my life

### Thinking about my health status...

I feel very discouraged due to my illness



I feel anxious when I try to manage my illness



I feel I have adjusted to my illness



I am generally optimistic about my future and my health condition

### Thinking about my health status...

I feel totally oppressed by my illness



I am upset when a new symptom arises



I feel I have accepted my illness



I can give sense to my life despite my illness condition

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