



# International Kidney Cancer Coalition Global Survey 2020

India Country Report

July 2021

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

[www.picker.org](http://www.picker.org)



## International Kidney Cancer Coalition (IKCC)

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

Priority areas of focus include:

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

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

## Picker

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

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## 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<sup>2</sup> (IKCC) has partnered with Affiliate Organisations to establish a biennial global survey, which launched in 2018. This programme invites the organisation's affiliates and members to contribute to the collection of feedback on patient experience. The results are used to ensure that patients' voices are heard and to drive planning and sharing of best practice.

In 2020, the IKCC appointed Picker<sup>3</sup> 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: 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 measure of the psychological experience of patients' engagement in their own care

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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.

<sup>2</sup> **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. Its 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.

<sup>3</sup> **Picker** is an international charity dedicated to ensuring the highest quality health and social care for all.

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, between October 2020 and January 2021. See Appendix 3: Methodology for more information.

Please note, this survey ran during the global coronavirus pandemic and responses may have been influenced by people's experiences during these unprecedented times.

## Survey activity

This report outlines the results from the **163** respondents from India. Comprised of:

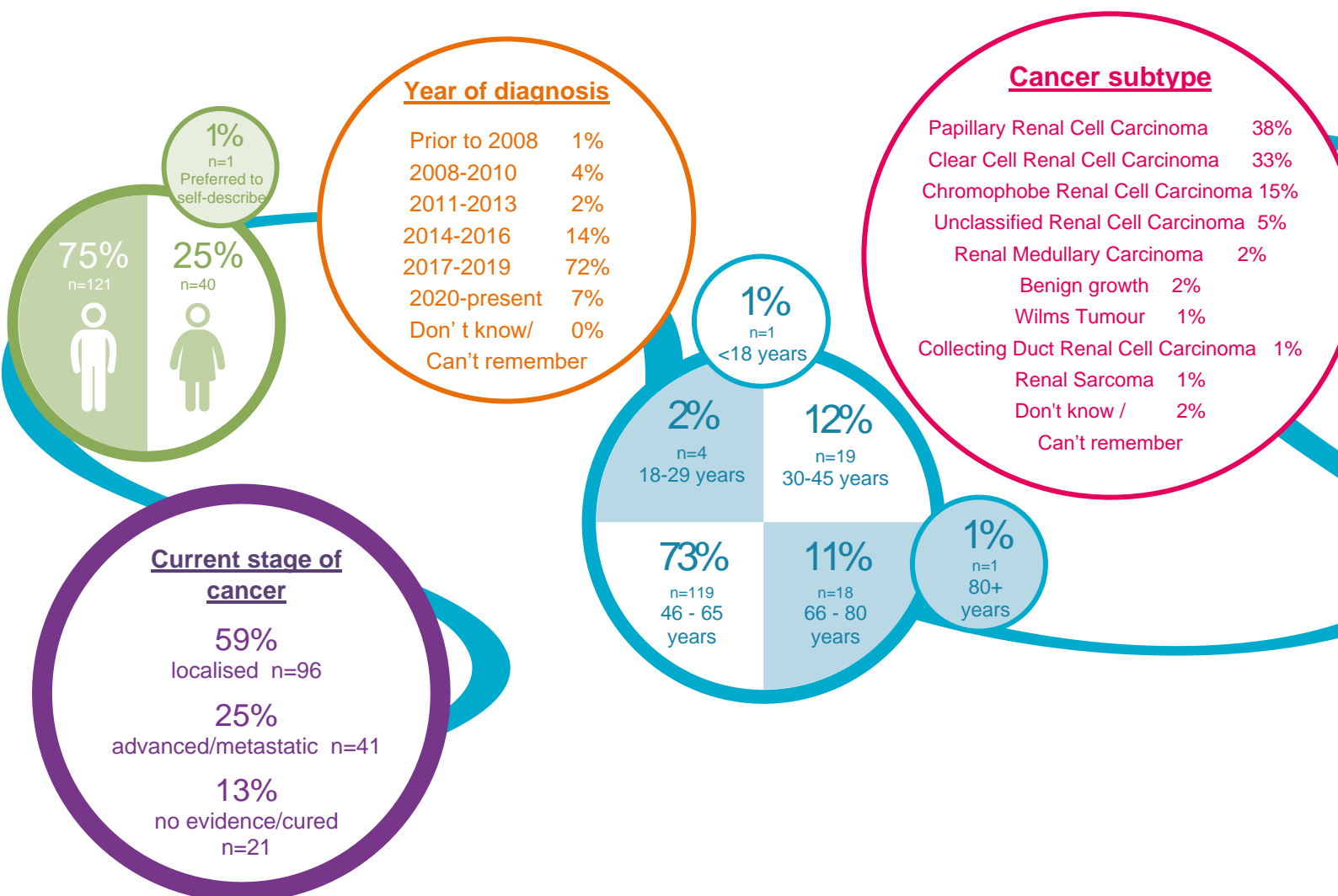


**116** patients



**46** carers or caregivers

**1** undisclosed



## Key results

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

Time to diagnosis – see page 6



**65%** 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 7



**42%** 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 7



**96%** of respondents completely or to some extent understood 'treatment options', at diagnosis

**94%** felt that 'treatment recommendations' were completely/to some extent understood at diagnosis

**4%** reported that the likelihood of surviving their cancer beyond five years was not explained

Barriers to treatment – see page 8



**98%** of respondents reported experiencing barriers to treatment

Biopsy – see page 8



**86%** of respondents had a biopsy (75% of the kidney; 12% of other sites)

**7%** of respondents were offered a biopsy but refused the procedure.

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

Awareness of clinical trials – see page 9



**66%** of respondents indicated that “No one” discussed cancer clinical trials with them.

Experience of clinical trials – see page 10



**20%** of respondents were invited to take part in a clinical trial

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

Level of physical activity – see page 10



**83%** of respondents self-reported that they were insufficiently active or completely sedentary

Psychosocial wellbeing – see page 10



**91%** of respondents indicated that they ‘very often’ or ‘always’ experienced general anxiety

**88%** of respondents indicated that they ‘very often’ or ‘always’ experienced disease-related anxiety

**83%** of respondents ‘very often’ or ‘always’ experienced stress related to financial issues

Seeking support – see page 11



**92%** of respondents reported having talked to their doctor / healthcare professional about their concerns

## Summary of results – India

Results are summarised by the following areas of focus:

- Patient knowledge, expectations of treatment and shared decision making:
  - Recency of diagnosis
  - Stage of kidney tumour(s) at diagnosis
  - Time to correct diagnosis
  - Knowledge at time of diagnosis
  - Getting a second opinion
  - Involvement in developing a treatment plan/shared decision making
  - Sources of help with shared decision making
  - Barriers to treatment
  - Stage of kidney tumour(s) today
  - Biopsy practice
  - Understanding of care and treatment
- Clinical trials, research awareness and sources of information
  - Awareness of clinical trials
  - Taking part in clinical trials
- Quality of life and overall health status of respondents
  - Physical activity
  - Psychosocial wellbeing
  - Sources of support
  - Patient health engagement

Any comparison to global data in this report refers to the 2,012 patient and carer/caregiver responses across 41 countries globally. Any reference to comparator countries refers to the following countries, each of which received over 100 survey responses:

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



For graphical representations outlined in this summary, please see Appendix 1: Graphical Results – India.

For all data and respondent counts, please see Appendix 2: Frequency Tables.

## Patient knowledge, expectations of treatment and self-reported “Patient Activation”

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 ensure patient understanding of the details of their specific diagnosis.

### Recency of diagnosis

7% (n=11) of respondents from India received a diagnosis in the year prior to taking to the survey (between 2020 and 2021). 72% (n=115) of respondents received a diagnosis between 2017 and 2019, whereas 21% (n=34) received a diagnosis in 2016 or prior<sup>4</sup>.

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

58% (n=94) of respondents who were residents of India indicated that their tumour was less than 4cm (stage 1A) when they first received a correct diagnosis. Globally, 23% (n=457) of respondents were stage 1A when they were first correctly diagnosed.

2% (n=4) of respondents from India indicated that they had not been told the stage of the kidney tumour at the time when they first received a correct diagnosis. This is on par with the global result (2%, n=41)

### 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. In India, only 4% (n=7) of respondents reported receiving a diagnosis in under 1 month.

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<sup>4</sup> Please note, it is important to recognise that there may be some recall issues relating to experience of diagnosis for those that were diagnosed a long time ago when being.

## Knowledge at time of diagnosis

Globally there were several areas, where at diagnosis, respondents indicate that they lacked knowledge. For example, 52%<sup>5</sup> (n=909) of respondents reported not being told what subtype of kidney cancer they had when they were first correctly diagnosed. 27% (n=25) of respondents in India indicated that this was the case.

At diagnosis (India respondents):

- 96% (n=151) completely or to some extent understood 'stage of cancer' (Globally this was 85%, n=1576)
- 96% (n=152) completely or to some extent understood 'treatment options' (Globally this was 88%, n=1603)
- 94% (n=147) felt that 'treatment recommendations' were completely/to some extent understood (Globally 88%, n=1569)
- 14% (n=22) said that cancer subtype was not explained (Globally 34%, n=587)
- 4% (n=6) said that risk of recurrence was not explained (Globally 31%, n=550)
- 4% (n=6) reported that the likelihood of surviving their cancer beyond five years was not explained (Globally 42%, n=720)

## Getting a second opinion

Upon receipt of a diagnosis, 77% (n=123) of respondents in India reported ever having received a second opinion (globally 38%, n=733). 20% (n=32) reported that they decided not to get a second opinion (globally 51%, n=982). Whereas nobody said that this was not an option to them (globally 4%, n=75) and 3% (n=5) indicated that they had never considered it (globally 7%, n=141).

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

With regards to developing a treatment plan, 51% (n=988) of respondents globally indicated that they were definitely as involved as much as they wanted to be in decisions about their treatment plan. In India, this accounted for 42% (n=65) of respondents.

## Sources of help with shared decision making

Very few respondents reported making treatment decisions alone. Globally, over half of responses (56%, n=1097) indicated that respondents involved their partner/spouse. In India,

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<sup>5</sup> In the interest of accuracy and ensuring that results are representative, for the purposes of reporting, respondents for whom a question was not applicable have been removed. These are those who have given responses such as "I do not need this", "Not sure" or "Don't know / Can't remember". See Appendix 3: Methodology for more information. For full frequency tables, please see Appendix 2.

74% (n=120) indicated that this was the case. In addition, 71% (n=115) indicated that their friends/other family members were involved.

### **Barriers to treatment**

2% of respondents (n=3) reported experiencing no barriers to treatment, relative to 44% (n=839) globally. The 5 most commonly experienced barriers reported from respondents in India were:

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

### **Stage of kidney tumour(s) today**

At the time of completing the survey, 13% (n=21) of respondents in India indicated that they had no evidence of disease / were cured. 59% (n=96) of respondents noted that their tumour was still only within the kidney (stage 1 or 2). Whereas 25% (n=41) of respondents indicated that their cancer was advanced/metastasised.

### **Biopsy practice**

Overall, 86% (n=134) of respondents in India had a biopsy, 75% (n=116) of a kidney growth and 12% (n=18) of another part of their body. This is compared with 45% (n=829) of respondents globally, of which 30% (n=550) were biopsies of a kidney growth and 15% (n=279) were biopsies of another site.

On the contrary, 5% (n=7) of respondents in India indicated that their tissue was looked at after they had surgery to remove it. Globally, this was 36% (n=664) of respondents. A further 2% (n=3) reported that they were never offered a biopsy – 17% (n=314) globally while 7% (n=11) were offered a biopsy but refused the procedure (3%, n=47 globally).

Of the 10 respondents in India who were not offered a biopsy, 7 of these would be willing to have one in the future.

## Understanding of care and treatment

The survey also asked respondents to consider their level of understanding of their care and treatment today.

In India, over 90% of respondents agreed/strongly agreed that they understood the following:

- local guidelines for kidney cancer follow up (96%, n=152 of respondents, globally 69%, n=1203)
- surgical options (94%, n=153 of respondents, globally 90%, n=1637)
- radiation therapy options (94%, n=151 of respondents, globally 67%, n=1000)
- the role of nutrition/lifestyle on their wellbeing (96%, n=152 of respondents, globally 78%, n=1393)
- local guidelines for kidney cancer care (94%, n=150 of respondents, globally 64%, n=1081)
- complementary therapies (e.g. meditation, etc.) (92%, n=146 of respondents, globally 57%, n=949)

In India, over one in four respondents disagreed/strongly disagreed that they understood the following:

- palliative care (37%, n=59 of respondents, globally 13%, n=191)
- immunotherapy options (31%, n=50 of respondents, globally 11%, n=179)
- active surveillance (30%, n=48 of respondents, globally 10%, n=171)
- ablative therapy options (30%, n=48 of respondents, globally 19%, n=293)
- targeted therapy options (26%, n=42 of respondents, globally 11%, n=175)

## Clinical trials, research awareness and sources of information

The IKCC recognises clinical trials as the cornerstone for advancing treatment in kidney cancer.

### Awareness of clinical trials

66% of respondents in India (n=108) indicated that no one spoke to them about cancer clinical trials. Of those that did discuss cancer clinical trials, 51% (n=28) indicated that clinical trials had been discussed with a patient organisation/support group, and 47% (n=26) said with a doctor/nurse.

### Taking part in clinical trial

Only 1 in 5 respondents (20% n=16) who were residents of India were invited to participate in a cancer clinical trial, compared with 31% (n=549) globally. Too few respondents in India reported taking part in a cancer clinical trial to assess overall experience.

Respondents were asked how likely it is that they would participate in a cancer clinical trial if they had been or were yet to be invited. The majority of respondents (52%, n=77) reported that it was neither likely nor unlikely that they would participate. However, 31% (n=45) reported that they would likely participate if invited and 4 respondents (3%) indicated that it would be very likely.

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

It is important to consider participants overall quality of life and health status. The 2020 IKCC global patient survey considered: current levels of physical activity within the respondents; overall psychosocial wellbeing; and patient health engagement using the Patient Health Engagement Scale (PHE-S).

#### 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. 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.

83% of respondents in India (n=130) self-reported that they were insufficiently active/completely sedentary. This is compared with 46% of respondents globally (n=830) and higher than all other comparator countries. 7% of respondents in India (n=11) reported physical levels to be within guidelines (150-299 minutes of physical activity per week).

#### Psychosocial wellbeing

Respondents from India have reported some of the worst levels of emotional wellbeing relative to global data.

Below are areas where the majority of respondents reported always/very often feeling emotional distress:

- 91% (n=149) of respondents reported that they very often/always felt general anxiety, compared with 43% (n=792) globally
- 88% (n=141) reported that they very often/always felt disease-specific anxiety, compared with 49% (n=904) globally

- 83% (n=135) always/often have stress relating to financial issues, compared with 26% (n=484) globally. Nobody in India said that this was never a concern.
- 82% (n=134) of respondents suggested that they always/very often had depression, relative to only 26% (n=480) globally
- 81% (n=131) said that they are always/often concerned about difficulty navigating the healthcare system, compared with 24% (n=437) globally
- 81% (n=131) always/very often worry about body image/changes in physical appearance, 27% (n=493) globally
- 76% (n=122) of respondents reported that they always/often are concerned about overall loss/reduction in employment, relative to 26% (n=466) globally
- 74% (n=120) said that they very often/always had the fear of recurrence, 55% (n=1003) globally
- 72% (n=117) always/often have concerns getting health or life insurance, 24% (n=435) globally
- 72% (n=117) of respondents reported that they always/often experience isolation, 24% (n=434) globally
- 71% (n=115) suggested that they always/often concerned with changes in relationships, 24% (n=439) globally
- 69% (n=112) of respondents always/often have difficulty in daily living, 27% (n=498) globally

## Sources of support

92% (n=135) of respondents in India who indicated that they have experienced at least one of the above concerns always/very often/sometimes said they had talked to a doctor/healthcare professional about their concerns. Globally, 52% (n=886) reported that they had consulted a doctor or other healthcare professional about their concerns.

Advice can not only be sought from healthcare professionals. Residents of India were the most likely of all comparator countries to report that they had contacted a patient support group (96%, n=157) compared with 64% (n=1179) of respondents globally. In fact, only 4% (n=6) of respondents in India said that they had not. This high number is an inherent bias of the survey, which was promoted by a patient support group in India.

When they contacted a patient support group, 67%, (n=105) of respondents in India 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 edition for the



2020 survey was the inclusion of the Patient Health Engagement Scale (PHE-S) developed from the Patient Health Engagement Model<sup>6</sup> (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 Graffigna defines as "Blackout" to "Eudaimonic project". 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).

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 respondents residing in India, please see the Frequency Tables in Appendix 2.

Analysing feedback from residents of India: (*Definitions from Graffigna et al., 2015*)

- 1% (n= 2) of respondents residing in India can be categorised as being in the 'Blackout – I am shocked' state (globally 5%, n=98)  
*The patients feel overwhelmed and shocked. They are emotionally fragile and they appear passive and withdrawn. They prefer to rely on others (i.e. caregivers, HCP) for significant decisions and action about their healthcare.*
- 12% (n=20) of respondents residing in India can be categorised as being in 'Arousal – I am a sick body' state (globally 31%, n=576)  
*The patients acquired a first knowledge about their health condition, and they are starting to copy with it, but they appear hypervigilant, anxious, over-reactive, very focused on the sick body.*
- 59% (n=96) of respondents residing in India were categorised in the 'Adhesion – I am a patient' state (globally 41%, n=760)  
*The patients accepted their condition, but they are still unable to navigate unexpected events related to their illness or their healthcare context. Easily they revert to arousal or blackout, focus is on the person as a patient.*
- 28% (n=45) of respondents residing in India were classified as the 'Meaning and purpose – I am a person' state (globally 22%, n=403)

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<sup>6</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.

*The patients appear balanced, they have fully accepted their health condition. They appear able to play an active role in their health and in the health of others, focus is on the person as a whole person with connections to many aspects of daily life, not only on their role as a patient.*

## Conclusions

This report presents data from residents of India 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. These results need to be interpreted at the local level by the Affiliate Organisations to determine the actionable findings that they wish to address locally.

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

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



## Acknowledgements

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

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

Most importantly, we would like to thank the patients and caregivers who took the time to complete the 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. Graphical Results – India
2. Frequency Tables – India
3. Methodology (Available as a separate document)

### **The following reports are also available in this series:**

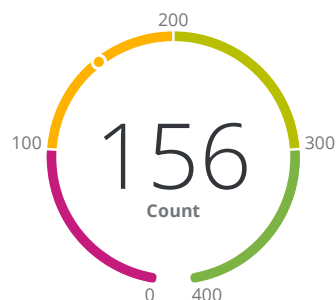
- International Kidney Cancer Coalition Survey 2020 – Global
- International Kidney Cancer Coalition Survey 2020 – Local

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

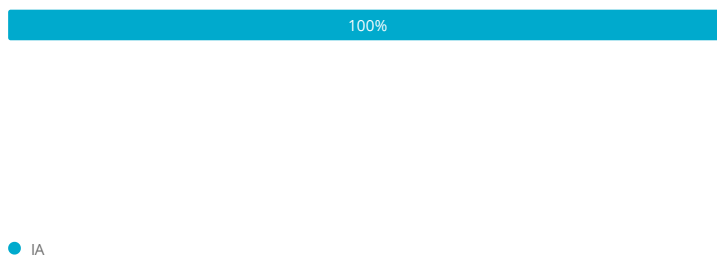
- |          |                            |
|----------|----------------------------|
| – Canada | – South Korea              |
| – India  | – United Kingdom – England |
| – France | – United States of America |
| – Japan  |                            |

## About the respondents

Response count

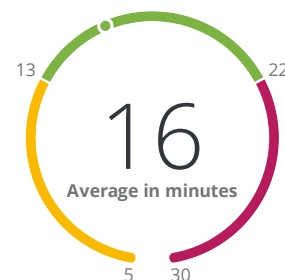


Responses per language 156 Responses

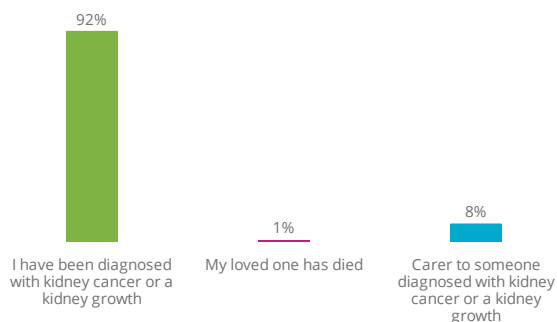


Average of minutes per response

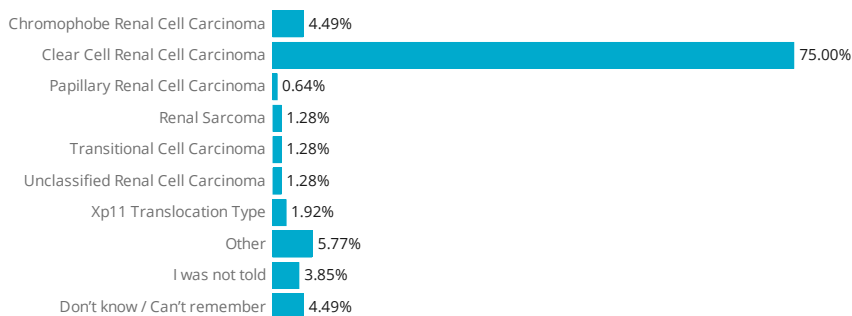
151 Responses



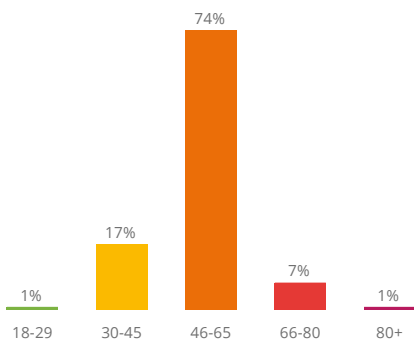
Described experience with kidney cancer 156 Responses



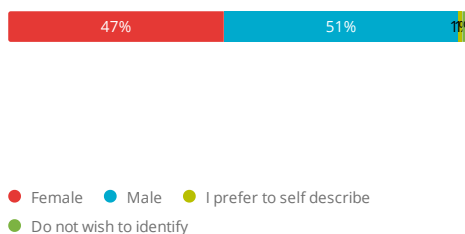
Sub-type of kidney cancer 156 Responses



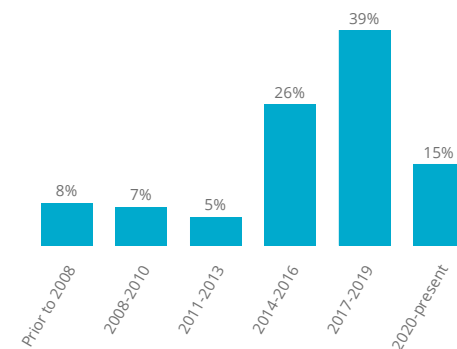
Age 156 Responses



Gender 156 Responses

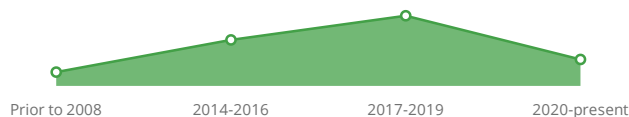


Diagnosis Year 155 Responses



### Diagnosis

Diagnosis Year 155 Responses



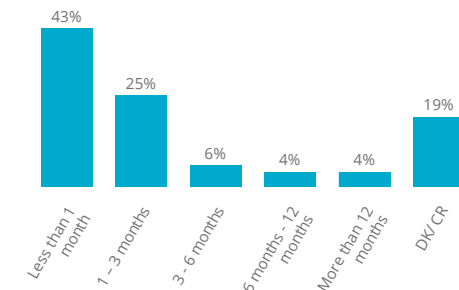
When first diagnosed were you told what subtype? 156 Responses



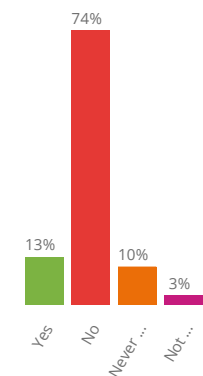
First correctly diagnosed 156 Responses



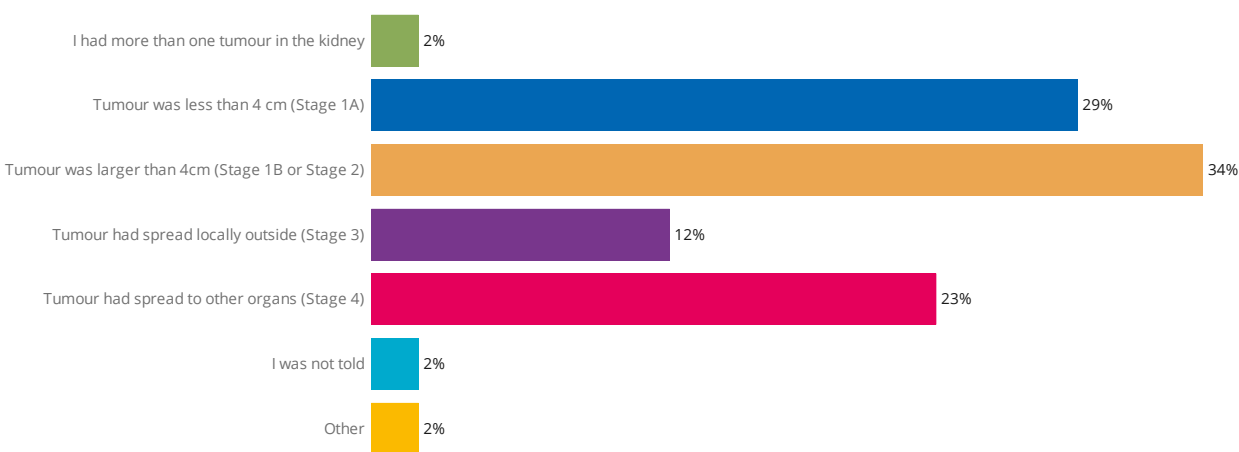
How long was it from the time you first thought something might be wrong with you to being CORRECTLY diagnosed? 154 Responses



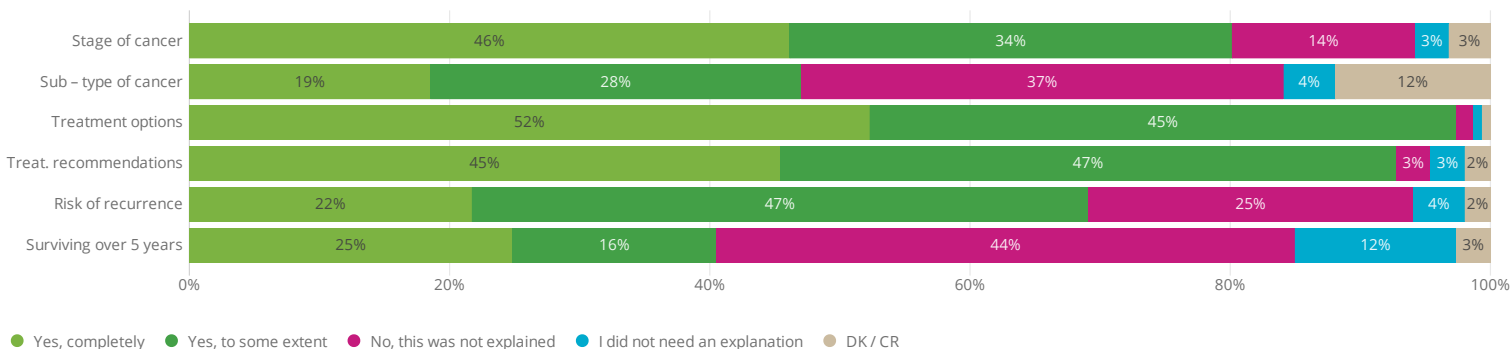
Did you ever seek a second opinion with a kidney cancer expert? 156 Responses



What stage when first diagnosed? 156 Responses

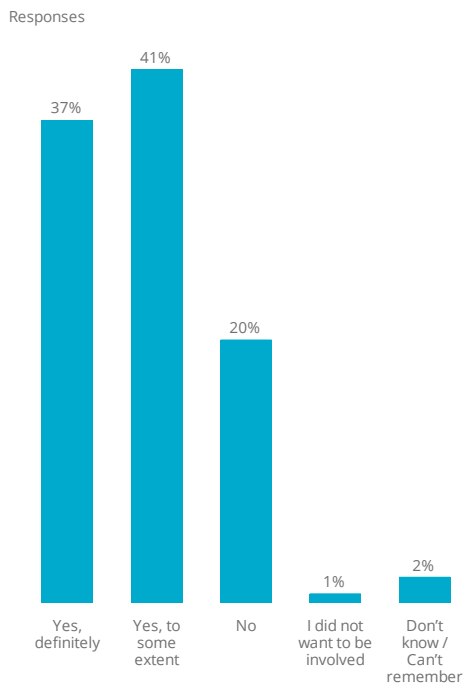


AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? 156 Responses

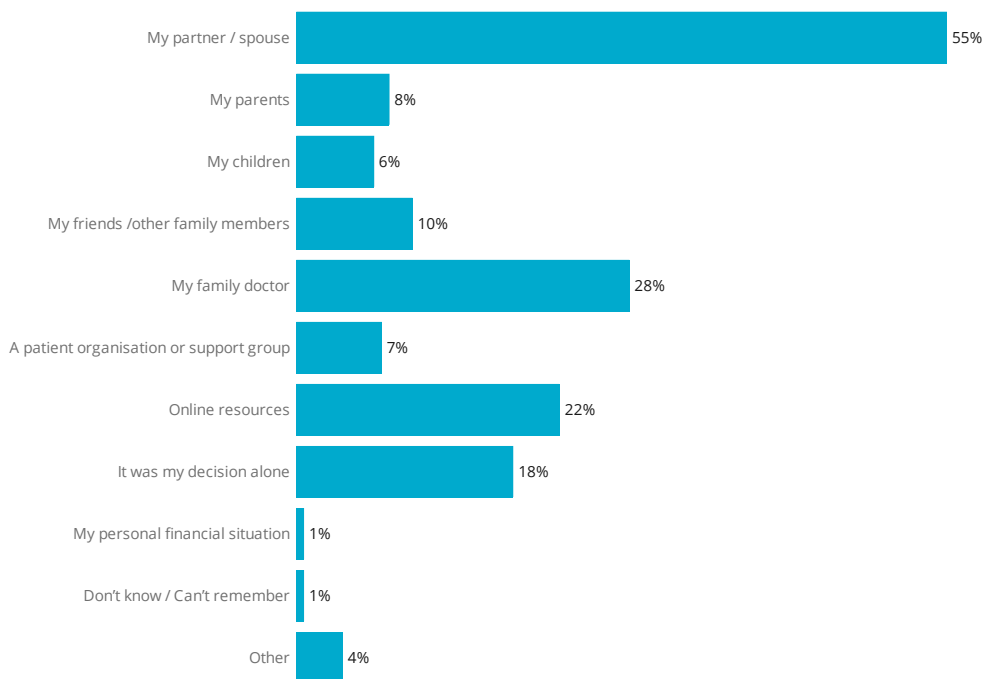


### Developing a treatment plan

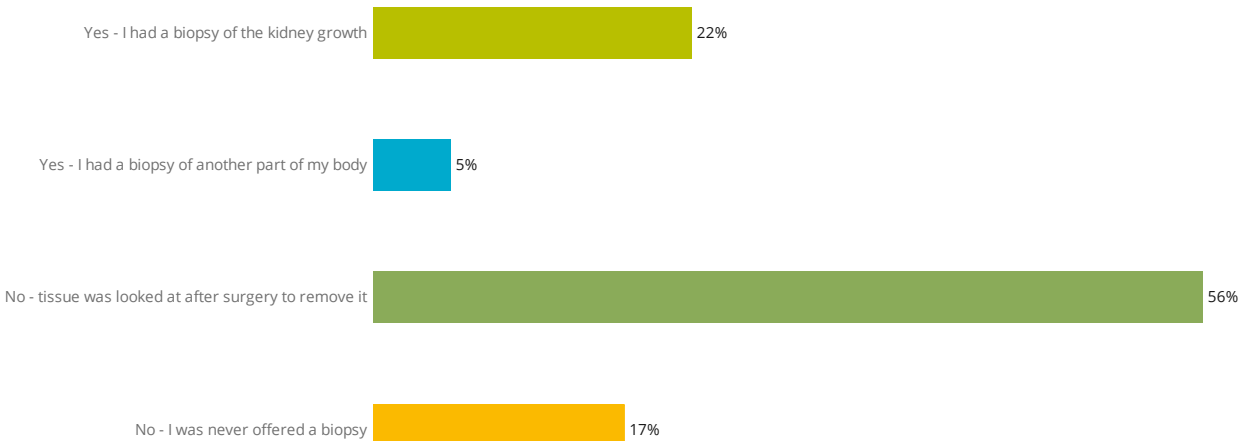
Were you involved as much as you wanted to be in decisions about your treatment plan? 155 Responses



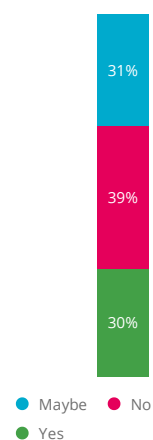
Who or what else helped you make decisions about your treatment plan? 154 Responses



Have you ever been offered a biopsy of some part of your body where kidney cancer was thought to be? 153 Responses



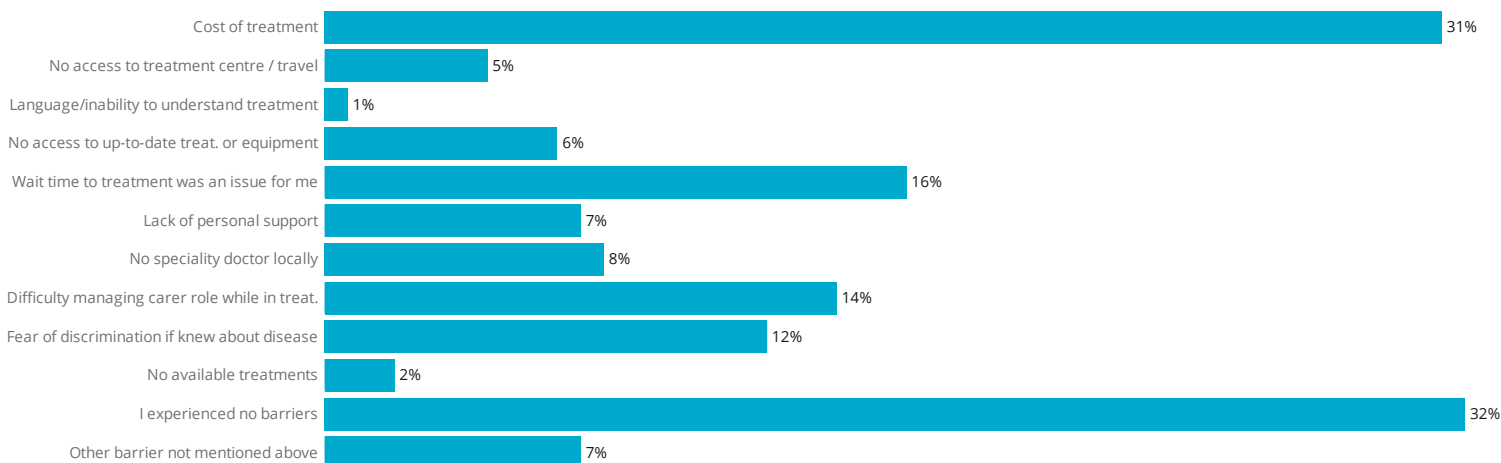
Would you be willing to have a biopsy in the future if necessary? 114 Responses



● Maybe ● No ● Yes

### Your care and treatment & your care today

Which barriers (if any) have you experienced in receiving treatment for your kidney cancer or kidney growth? 154 Responses

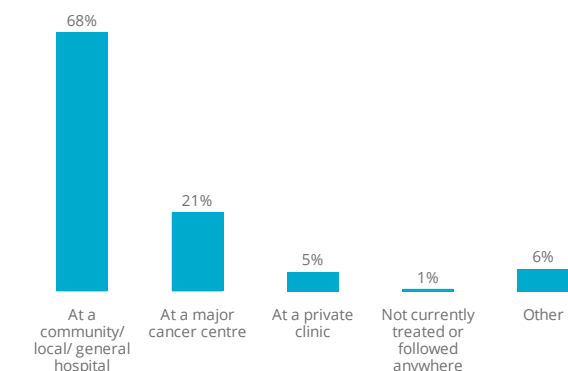


Which of the following best describes your stage of kidney cancer or kidney growth TODAY? 155 Responses

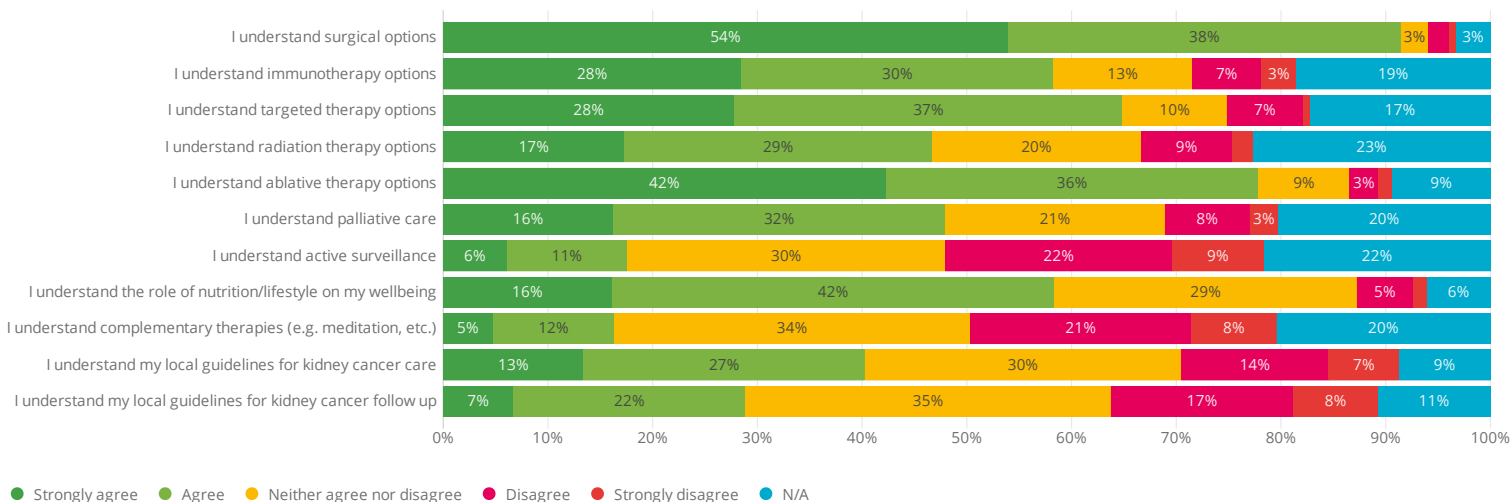


● I currently have no evidence of disease
 ● I was told that I am cured
 ● Kidney cancer / growth is still only within the kidney (Stage 1 or Stage 2)
 ● Kidney cancer / growth is still locally advanced (Stage 3)
 ● Kidney cancer / growth has spread to other organs or distant sites (Stage 4)
 ● Don't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

Where are you CURRENTLY being treated or followed? 155 Responses

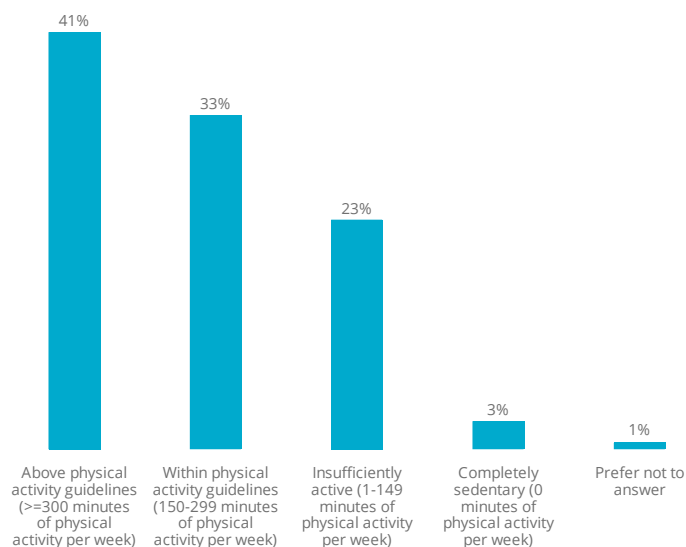


To what extent do you agree or disagree with the following statements?

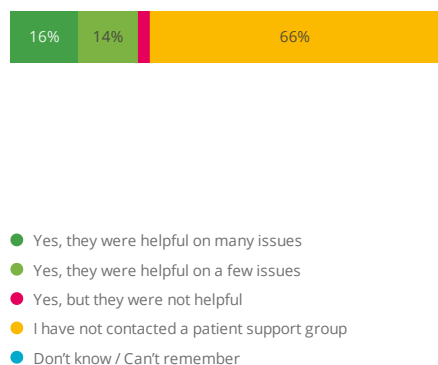


### Quality of life

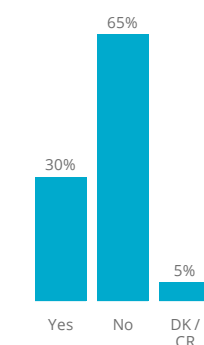
Current level of leisure-time physical activity 146 Responses



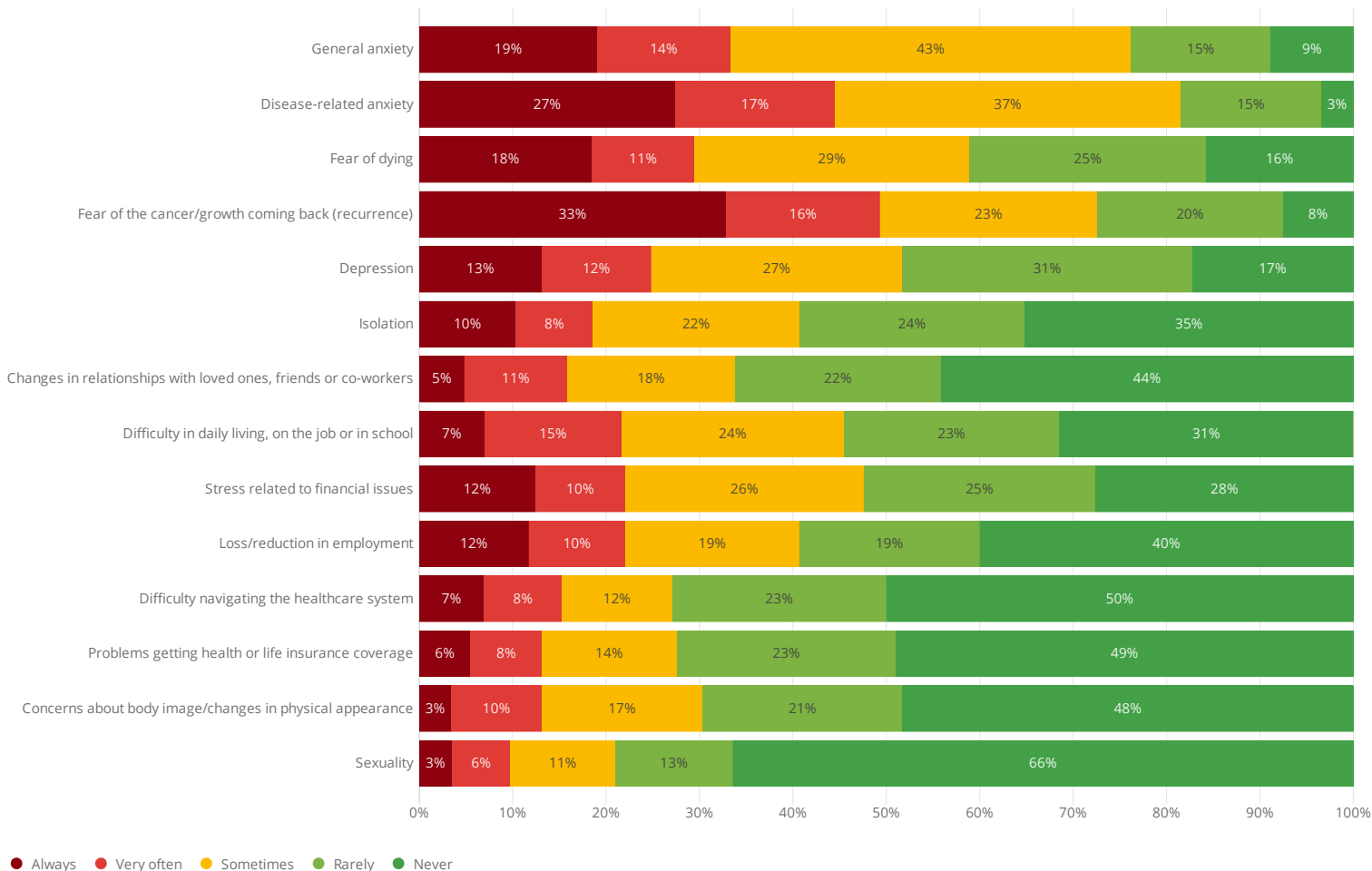
Have you ever used a patient support group (either in person or online) to help you with your kidney cancer / growth? 148 Responses



Have you ever talked to your doctor or to any other healthcare professional about any of these concerns? 132 Responses

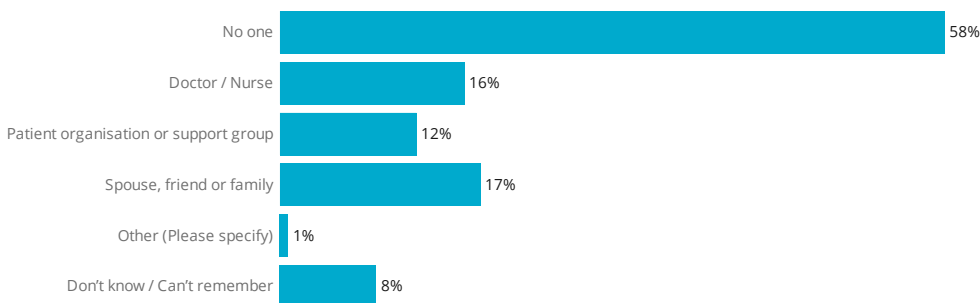


How often have the following impacted your sense of emotional well-being since your diagnosis?

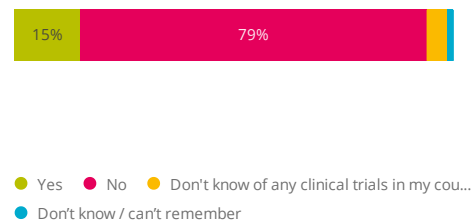


## Cancer clinical trials

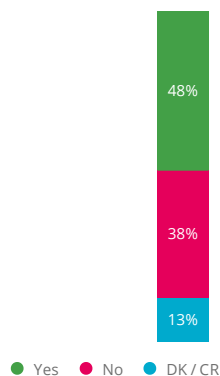
Who, if anyone, has discussed cancer clinical trials with you? 144 Responses



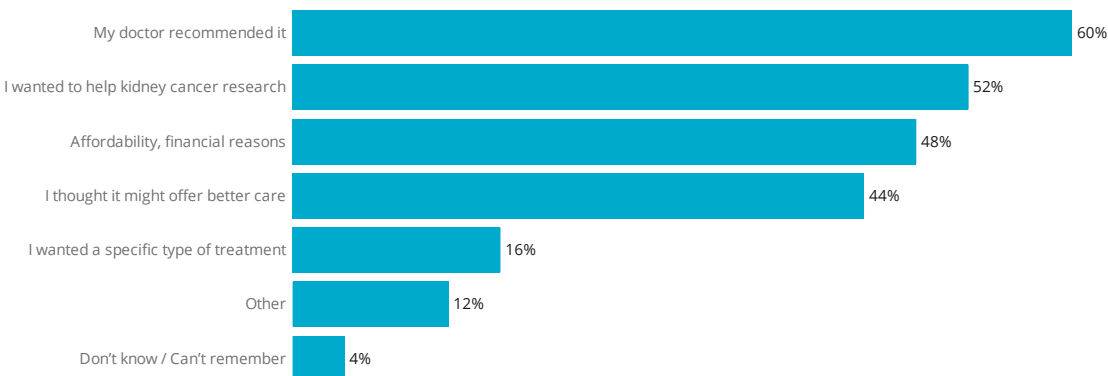
Have you ever been invited to participate in a cancer clinical trial? 147 Responses



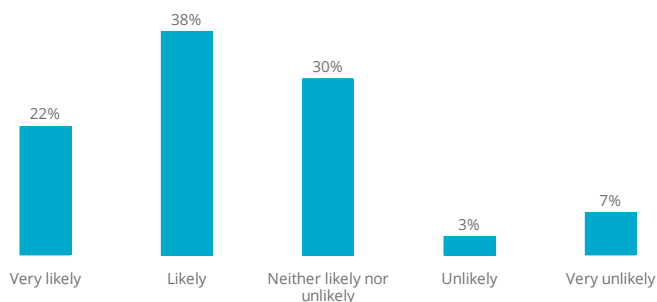
Did you agree to participate in the cancer clinical trial? 52 Responses



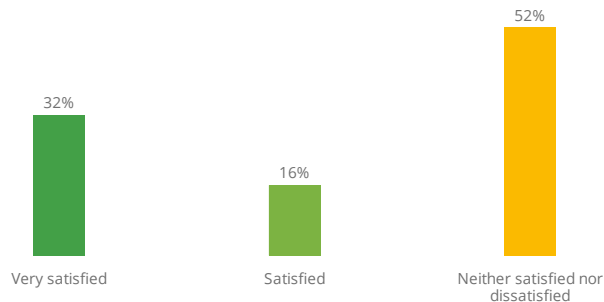
Why did you agree to participate? 25 Responses



If you had been or were invited, how likely is it that you would participate in a cancer clinical trial? 124 Responses



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



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

Thinking about my health status... 141 Responses



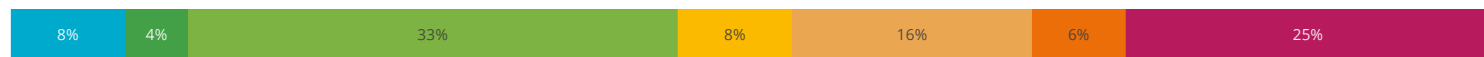
● I feel in blackout ● I feel in blackout/I feel on the alert ● I feel on the alert ● I feel on the alert/I am aware ● I am aware ● I am aware/I feel positive ● I feel positive

Thinking about my health status... 142 Responses



● I feel dazed ● I feel dazed/I am in alarm ● I am in alarm ● I am in alarm/I am conscious ● I am conscious ● I am conscious/I feel serene ● I feel serene

Thinking about my health status... 142 Responses



● When I think about my illness I feel overwhelmed by emotions ● I feel overwhelmed by emotions/anxious every time a new symptom arises ● I feel anxious every time a new symptom arises  
● Anxious every time a new symptom arises/I have got used to my illness condition ● I have got used to my illness condition  
● I have got used to my illness condition/Despite my illness I perceive coherence and continuity in my life ● Despite my illness I perceive coherence and continuity in my life

Thinking about my health status... 140 Responses



● I feel very discouraged due to my illness ● I feel very discouraged due to my illness/I feel anxious when I try to manage my illness ● I feel anxious when I try to manage my illness  
● I feel anxious when I try to manage my illness/I feel I have adjusted to my illness ● I feel I have adjusted to my illness  
● I feel I have adjusted to my illness/I am generally optimistic about my future and my health condition ● I am generally optimistic about my future and my health condition

Thinking about my health status... 141 Responses



● I feel totally oppressed by my illness/I am upset when a new symptom arises ● I feel I have accepted my illness ● I am upset when a new symptom arises/I feel I have accepted my illness  
● I feel I have accepted my illness/I can give sense to my life despite my illness condition ● I can give sense to my life despite my illness condition ● I feel totally oppressed by my illness  
● I am upset when a new symptom arises



### About the respondents

#### About respondent 156 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	143	92%
I am a carer or caregiver to someone who has been diagnosed with kidney cancer or a kidney growth	12	8%
My loved one has died	1	1%
Total	156	100%

#### Sub-type of kidney cancer 156 Responses

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

Count ▲ Percent

Clear Cell Renal Cell Carcinoma	117	75%
Other	9	6%
Don't know / Can't remember	7	4%
Chromophobe Renal Cell Carcinoma	7	4%
I was not told	6	4%
Xp11 Translocation Type	3	2%
Unclassified Renal Cell Carcinoma	2	1%
Transitional Cell Carcinoma (Urothelial Carcinoma)	2	1%
Renal Sarcoma (NOT Renal Cell Carcinoma with Sarcomatoid Appearance)	2	1%
Papillary Renal Cell Carcinoma	1	1%
Total	156	100%

#### Gender 156 Responses

Q5 - What is your gender?

Count ▲ Percent

Male	79	51%
Female	74	47%
Do not wish to identify	2	1%
I prefer to self describe	1	1%
Total	156	100%

#### Age 156 Responses

Q4 - What is your age now?

Count ▲ Percent

46-65	116	74%
30-45	27	17%
66-80	11	7%
80+	1	1%
18-29	1	1%
Total	156	100%

#### Country of residence 156 Responses

Q3 - In which country do you currently reside?

Count Percent

Japan	156	100%
Total	156	100%

### Diagnosis

#### Diagnosis Year 155 Responses

Q6 - In what year were you diagnosed?	Count ▲	Percent
2017-2019	61	39%
2014-2016	40	26%
2020-present	23	15%
Prior to 2008	12	8%
2008-2010	11	7%
2011-2013	8	5%
Total	155	100%

#### First correctly diagnosed 156 Responses

Q7 - Where was your kidney growth FIRST CORRECTLY DIAGNOSED?	Count ▲	Percent
Community/local/general hospital	122	78%
Private clinic	10	6%
My family doctor's office	7	4%
Major cancer centre by a specialist	6	4%
Other	5	3%
Major cancer centre	5	3%
Emergency department	1	1%
Total	156	100%

#### When first diagnosed were you told what subtype? 156 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	88	56%
Yes	57	37%
Not sure	11	7%
Total	156	100%

#### When first diagnosed were you told what subtype? - Positive Score 145 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	88	61%
Yes	57	39%
Total	145	100%

#### What stage when first diagnosed? 156 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)	53	34%
Tumour was less than 4 cm (Stage 1A)	45	29%
Tumour had spread to other organs (Stage 4)	36	23%
Tumour had spread locally outside (Stage 3)	19	12%
Other	3	2%
I was not told	3	2%
I had more than one tumour in the kidney	3	2%
Total	162	104%

### Diagnosis

#### How long to correct diagnosis? 154 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	66	43%
1 – 3 months	38	25%
DK/ CR	29	19%
3 - 6 months	9	6%
More than 12 months	6	4%
6 months - 12 months	6	4%
Total	154	100%

#### How long to correct diagnosis? - Positive Score 125 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	66	53%
1 – 3 months	38	30%
3 - 6 months	9	7%
More than 12 months	6	5%
6 months - 12 months	6	5%
Total	125	100%

#### Explanation at diagnosis - Stage of cancer 156 Responses

Q11a - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Stage of cancer	Count ▲	Percent
Yes, completely	72	46%
Yes, to some extent	53	34%
No, this was not explained	22	14%
Don't know / can't remember	5	3%
I did not need an explanation	4	3%
Total	156	100%

#### Explanation at diagnosis - Stage of cancer - Positive Score 147 Responses

Q11a+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Stage of cancer	Count ▲	Percent
Yes, completely	72	49%
Yes, to some extent	53	36%
No, this was not explained	22	15%
Total	147	100%

#### Explanation at diagnosis - Subtype of cancer 151 Responses

Q11b - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Subtype of cancer	Count ▲	Percent
No, this was not explained	56	37%
Yes, to some extent	43	28%
Yes, completely	28	19%
Don't know / can't remember	18	12%
I did not need an explanation	6	4%
Total	151	100%

#### Explanation at diagnosis - Subtype of cancer - Positive Score 127 Responses

Q11b+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Subtype of cancer	Count ▲	Percent
No, this was not explained	56	44%
Yes, to some extent	43	34%
Yes, completely	28	22%
Total	127	100%

### Diagnosis

#### Explanation at diagnosis - Treatment options 153 Responses

Q11c - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment options	Count ▲	Percent
Yes, completely	80	52%
Yes, to some extent	69	45%
No, this was not explained	2	1%
I did not need an explanation	1	1%
Don't know / can't remember	1	1%
Total	153	100%

#### Explanation at diagnosis - Treatment options - Positive Score 151 Responses

Q11c+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment options	Count ▲	Percent
Yes, completely	80	53%
Yes, to some extent	69	46%
No, this was not explained	2	1%
Total	151	100%

#### Explanation at diagnosis - Treatment recommendations 152 Responses

Q11d - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment recommendations	Count ▲	Percent
Yes, to some extent	72	47%
Yes, completely	69	45%
No, this was not explained	4	3%
I did not need an explanation	4	3%
Don't know / can't remember	3	2%
Total	152	100%

#### Explanation at diagnosis - Treatment recommendations - Positive Score

145 Responses

Q11d+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment recommendations	Count ▲	Percent
Yes, to some extent	72	50%
Yes, completely	69	48%
No, this was not explained	4	3%
Total	145	100%

#### Explanation at diagnosis - Risk of recurrence 152 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	72	47%
No, this was not explained	38	25%
Yes, completely	33	22%
I did not need an explanation	6	4%
Don't know / can't remember	3	2%
Total	152	100%

#### Explanation at diagnosis - Risk of recurrence - Positive Score 143 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	72	50%
No, this was not explained	38	27%
Yes, completely	33	23%
Total	143	100%

### Diagnosis

#### Explanation at diagnosis - Likelihood of surviving beyond 5 yrs 153 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	68	44%
Yes, completely	38	25%
Yes, to some extent	24	16%
I did not need an explanation	19	12%
Don't know / can't remember	4	3%
Total	153	100%

#### Explanation at diagnosis - Likelihood of surviving beyond 5 yrs - Positive Score 130 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	68	52%
Yes, completely	38	29%
Yes, to some extent	24	18%
Total	130	100%

#### Second opinion 156 Responses

Q12 - Did you ever seek a second opinion with a kidney cancer expert?

Count ▲ Percent

No	116	74%
Yes	20	13%
Never considered it	16	10%
Not available to me	4	3%
Total	156	100%

### Developing a treatment plan

#### Involvement in treatment plan 155 Responses

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

	Count ▲	Percent
Yes, to some extent	63	41%
Yes, definitely	57	37%
No	31	20%
Don't know / Can't remember	3	2%
I did not want to be involved	1	1%
Total	155	100%

#### Involvement in treatment plan - Positive Score 151 Responses

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

	Count ▲	Percent
Yes, to some extent	63	42%
Yes, definitely	57	38%
No	31	21%
Total	151	100%

#### Support in treatment plan decisions 154 Responses

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

	Count ▲	Percent
My partner / spouse	84	55%
My family doctor	43	28%
Online resources	34	22%
It was my decision alone	28	18%
My friends /other family members	15	10%
My parents	12	8%
A patient organisation or support group	11	7%
My children	10	6%
Other	6	4%
My personal financial situation	1	1%
Don't know / Can't remember	1	1%
Total	245	159%

#### Barriers to treatment 154 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	49	32%
Cost of treatment	48	31%
Wait time to treatment was an issue for me	25	16%
Difficulty managing carer role while in treat.	22	14%
Fear of discrimination if knew about disease	19	12%
No speciality doctor locally	12	8%
Other barrier not mentioned above	11	7%
Lack of personal support	11	7%
No access to up-to-date treat. or equipment	10	6%
No access to treatment centre / travel	7	5%
No available treatments	3	2%
Language/inability to understand treatment	1	1%
Total	218	142%

### Your care and treatment & your care today

#### Stage of kidney cancer or kidney growth TODAY 155 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)	71	46%
I currently have no evidence of disease	45	29%
Other (Please specify)	16	10%
I was told that I am cured	11	7%
Kidney cancer / growth is still only within the kidney (Stage 1 or Stage 2)	9	6%
Kidney cancer / growth is still locally advanced (Stage 3)	2	1%
Don't know / Can't remember	1	1%
Total	155	100%

#### Understanding of care/treatment - Surgical options 152 Responses

Q18a - I understand surgical options	Count ▲	Percent
Strongly agree	82	54%
Agree	57	38%
N/A	5	3%
Neither agree nor disagree	4	3%
Disagree	3	2%
Strongly disagree	1	1%
Total	152	100%

#### Understanding of care/treatment - Immunotherapy options 151 Responses

Q18b - I understand immunotherapy options	Count ▲	Percent
Agree	45	30%
Strongly agree	43	28%
N/A	28	19%
Neither agree nor disagree	20	13%
Disagree	10	7%
Strongly disagree	5	3%
Total	151	100%

#### Treatment TODAY 155 Responses

Q17 - Where are you CURRENTLY being treated or followed?	Count ▲	Percent
At a community/ local/ general hospital	105	68%
At a major cancer centre	32	21%
Other	9	6%
At a private clinic	8	5%
Not currently treated or followed anywhere	1	1%
Total	155	100%

#### Understanding of care/treatment - Surgical options - Positive Score 147 Responses

Q18a+ - I understand surgical options	Count ▲	Percent
Strongly agree	82	56%
Agree	57	39%
Neither agree nor disagree	4	3%
Disagree	3	2%
Strongly disagree	1	1%
Total	147	100%

#### Understanding of care/treatment - Immunotherapy options - Positive Score 123 Responses

Q18b+ - I understand immunotherapy options	Count ▲	Percent
Agree	45	37%
Strongly agree	43	35%
Neither agree nor disagree	20	16%
Disagree	10	8%
Strongly disagree	5	4%
Total	123	100%

## Your care and treatment & your care today

### Understanding of care/treatment - Targeted therapy options 151 Responses

Q18c - I understand targeted therapy options	Count ▲	Percent
Agree	56	37%
Strongly agree	42	28%
N/A	26	17%
Neither agree nor disagree	15	10%
Disagree	11	7%
Strongly disagree	1	1%
Total	151	100%

### Understanding of care/treatment - Targeted therapy options - Positive Score 125 Responses

Q18c+ -I understand targeted therapy options	Count ▲	Percent
Agree	56	45%
Strongly agree	42	34%
Neither agree nor disagree	15	12%
Disagree	11	9%
Strongly disagree	1	1%
Total	125	100%

### Understanding of care/treatment - Radiation therapy options 150 Responses

Q18d - I understand radiation therapy options	Count ▲	Percent
Agree	44	29%
N/A	34	23%
Neither agree nor disagree	30	20%
Strongly agree	26	17%
Disagree	13	9%
Strongly disagree	3	2%
Total	150	100%

### Understanding of care/treatment - Radiation therapy options - Positive Score 116 Responses

Q18d+ - I understand radiation therapy options	Count ▲	Percent
Agree	44	38%
Neither agree nor disagree	30	26%
Strongly agree	26	22%
Disagree	13	11%
Strongly disagree	3	3%
Total	116	100%

### Understanding of care/treatment - Ablative therapy options 149 Responses

Q18e - I understand ablative therapy options	Count ▲	Percent
Strongly agree	63	42%
Agree	53	36%
N/A	14	9%
Neither agree nor disagree	13	9%
Disagree	4	3%
Strongly disagree	2	1%
Total	149	100%

### Understanding of care/treatment - Ablative therapy options - Positive Score 135 Responses

Q18e+ - I understand ablative therapy options	Count ▲	Percent
Strongly agree	63	47%
Agree	53	39%
Neither agree nor disagree	13	10%
Disagree	4	3%
Strongly disagree	2	1%
Total	135	100%



### Your care and treatment & your care today

Understanding of care/treatment - Palliative 148 Responses

Q18f - I understand palliative care	Count ▲	Percent
Agree	47	32%
Neither agree nor disagree	31	21%
N/A	30	20%
Strongly agree	24	16%
Disagree	12	8%
Strongly disagree	4	3%
Total	148	100%

Understanding of care/treatment - Palliative - Positive Score 118 Responses

Q18f+ - I understand palliative care	Count ▲	Percent
Agree	47	40%
Neither agree nor disagree	31	26%
Strongly agree	24	20%
Disagree	12	10%
Strongly disagree	4	3%
Total	118	100%

Understanding of care/treatment - Active Surveillance 148 Responses

Q18g - I understand active surveillance	Count ▲	Percent
Neither agree nor disagree	45	30%
N/A	32	22%
Disagree	32	22%
Agree	17	11%
Strongly disagree	13	9%
Strongly agree	9	6%
Total	148	100%

Understanding of care/treatment - Active Surveillance - Positive Score 116 Responses

Q18g+ - I understand active surveillance	Count ▲	Percent
Neither agree nor disagree	45	39%
Disagree	32	28%
Agree	17	15%
Strongly disagree	13	11%
Strongly agree	9	8%
Total	116	100%

Understanding of care/treatment - Role of nutrition/lifestyle 149 Responses

Q18h - I understand the role of nutrition/lifestyle on my wellbeing	Count ▲	Percent
Agree	63	42%
Neither agree nor disagree	43	29%
Strongly agree	24	16%
N/A	9	6%
Disagree	8	5%
Strongly disagree	2	1%
Total	149	100%

Understanding of care/treatment - Role of nutrition/lifestyle - Positive Score 140 Responses

Q18h+ - I understand the role of nutrition/lifestyle on my wellbeing	Count ▲	Percent
Agree	63	45%
Neither agree nor disagree	43	31%
Strongly agree	24	17%
Disagree	8	6%
Strongly disagree	2	1%
Total	140	100%

### Your care and treatment & your care today

#### Understanding of care/treatment - Complementary therapies 147 Responses

Q18i - I understand complementary therapies (e.g. meditation, etc.)	Count ▲	Percent
Neither agree nor disagree	50	34%
Disagree	31	21%
N/A	30	20%
Agree	17	12%
Strongly disagree	12	8%
Strongly agree	7	5%
Total	147	100%

#### Understanding of care/treatment - Complementary therapies - Positive Score 117 Responses

Q18i+ - I understand complementary therapies (e.g. meditation, etc.)	Count ▲	Percent
Neither agree nor disagree	50	43%
Disagree	31	26%
Agree	17	15%
Strongly disagree	12	10%
Strongly agree	7	6%
Total	117	100%

#### Understanding of care/treatment - Local guidelines for care 149 Responses

Q18j - I understand my local guidelines for kidney cancer care	Count ▲	Percent
Neither agree nor disagree	45	30%
Agree	40	27%
Disagree	21	14%
Strongly agree	20	13%
N/A	13	9%
Strongly disagree	10	7%
Total	149	100%

#### Understanding of care/treatment - Local guidelines for care - Positive Score 136 Responses

Q18j+ - I understand my local guidelines for kidney cancer care	Count ▲	Percent
Neither agree nor disagree	45	33%
Agree	40	29%
Disagree	21	15%
Strongly agree	20	15%
Strongly disagree	10	7%
Total	136	100%

#### Understanding of care/treatment - Local guidelines for follow up 149 Responses

Q18k - I understand my local guidelines for kidney cancer follow up	Count ▲	Percent
Neither agree nor disagree	52	35%
Agree	33	22%
Disagree	26	17%
N/A	16	11%
Strongly disagree	12	8%
Strongly agree	10	7%
Total	149	100%

#### Understanding of care/treatment - Local guidelines for follow up - Positive Score 133 Responses

Q18k+ - I understand my local guidelines for kidney cancer follow up	Count ▲	Percent
Neither agree nor disagree	52	39%
Agree	33	25%
Disagree	26	20%
Strongly disagree	12	9%
Strongly agree	10	8%
Total	133	100%

## Your care and treatment & your care today

### Biopsy experience 153 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	86	56%
Yes - I had a biopsy of the kidney growth	33	22%
No - I was never offered a biopsy	26	17%
Yes - I had a biopsy of another part of my body	8	5%
Total	153	100%

### Biopsy 114 Responses

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

Count ▲ Percent

No	45	39%
Maybe	35	31%
Yes	34	30%
Total	114	100%

### Quality of life

#### Physical activity 146 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

Above physical activity guidelines ( $\geq 300$ minutes of physical activity per week)	60	41%
Within physical activity guidelines (150-299 minutes of physical activity per week)	48	33%
Insufficiently active (1-149 minutes of physical activity per week)	33	23%
Completely sedentary (0 minutes of physical activity per week)	4	3%
Prefer not to answer.	1	1%
Total	146	100%

#### Physical activity - Positive Score 145 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

Above physical activity guidelines ( $\geq 300$ minutes of physical activity per week)	60	41%
Within physical activity guidelines (150-299 minutes of physical activity per week)	48	33%
Insufficiently active (1-149 minutes of physical activity per week)	33	23%
Completely sedentary (0 minutes of physical activity per week)	4	3%
Total	145	100%

#### Emotional well-being - General anxiety 147 Responses

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

Count ▲ Percent

Sometimes	63	43%
Always	28	19%
Rarely	22	15%
Very often	21	14%
Never	13	9%
Total	147	100%

#### Emotional well-being - Disease related anxiety 146 Responses

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

Count ▲ Percent

Sometimes	54	37%
Always	40	27%
Very often	25	17%
Rarely	22	15%
Never	5	3%
Total	146	100%

#### Emotional well-being - Fear of dying 146 Responses

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

Count ▲ Percent

Sometimes	43	29%
Rarely	37	25%
Always	27	18%
Never	23	16%
Very often	16	11%
Total	146	100%

#### Emotional well-being - Fear of cancer/growth coming back 146 Responses

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

Count ▲ Percent

Always	48	33%
Sometimes	34	23%
Rarely	29	20%
Very often	24	16%
Never	11	8%
Total	146	100%

### Quality of life

#### Emotional well-being - Depression 145 Responses

Q22e - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Rarely	45	31%
Sometimes	39	27%
Never	25	17%
Always	19	13%
Very often	17	12%
Total	145	100%

#### Emotional well-being - Isolation 145 Responses

Q22f - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	51	35%
Rarely	35	24%
Sometimes	32	22%
Always	15	10%
Very often	12	8%
Total	145	100%

#### Emotional well-being - Changes in relationships 145 Responses

Q22g - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	64	44%
Rarely	32	22%
Sometimes	26	18%
Very often	16	11%
Always	7	5%
Total	145	100%

#### Emotional well-being - Difficulty in daily living 143 Responses

Q22h - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	45	31%
Sometimes	34	24%
Rarely	33	23%
Very often	21	15%
Always	10	7%
Total	143	100%

#### Emotional well-being - Stress related to financial issues 145 Responses

Q22i - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	40	28%
Sometimes	37	26%
Rarely	36	25%
Always	18	12%
Very often	14	10%
Total	145	100%

#### Emotional well-being - Loss/reduction in employment 145 Responses

Q22j - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	58	40%
Rarely	28	19%
Sometimes	27	19%
Always	17	12%
Very often	15	10%
Total	145	100%

### Quality of life

#### Emotional well-being - Difficulty navigating the healthcare system 144

Responses

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

Count ▲ Percent

Never	72	50%
Rarely	33	23%
Sometimes	17	12%
Very often	12	8%
Always	10	7%
Total	144	100%

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

145 Responses

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

Count ▲ Percent

Never	71	49%
Rarely	34	23%
Sometimes	21	14%
Very often	11	8%
Always	8	6%
Total	145	100%

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

145 Responses

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

Count ▲ Percent

Never	70	48%
Rarely	31	21%
Sometimes	25	17%
Very often	14	10%
Always	5	3%
Total	145	100%

#### Emotional well-being - Sexuality 143 Responses

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

Count ▲ Percent

Never	95	66%
Rarely	18	13%
Sometimes	16	11%
Very often	9	6%
Always	5	3%
Total	143	100%

## Quality of life

### Seeking support from medical professional 132 Responses

Q24 - Have you ever talked to your doctor or to any other healthcare professional about any of these concerns?

Count ▲ Percent

No	86	65%
Yes	40	30%
Don't know / Can't remember	6	5%
Total	132	100%

### Seeking support from medical professional - Positive Score 126 Responses

Q24+ - Have you ever talked to your doctor or to any other healthcare professional about any of these concerns?

Count ▲ Percent

No	86	68%
Yes	40	32%
Total	126	100%

### Seeking support from PSG 148 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	98	66%
Yes, they were helpful on many issues	23	16%
Yes, they were helpful on a few issues	20	14%
Yes, but they were not helpful	4	3%
Don't know / Can't remember	3	2%
Total	148	100%

### Seeking support from PSG - Positive Score 145 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	98	68%
Yes, they were helpful on many issues	23	16%
Yes, they were helpful on a few issues	20	14%
Yes, but they were not helpful	4	3%
Total	145	100%

### Cancer clinical trials

#### Discussion with whom 144 Responses

Q26 - Who, if anyone, has discussed cancer clinical trials with you? (PLEASE CHOOSE ALL THAT APPLY)

	Count ▲	Percent
No one	83	58%
Spouse, friend or family	25	17%
Doctor / Nurse	23	16%
Patient organisation or support group	17	12%
Don't know / Can't remember	12	8%
Other (Please specify)	1	1%
Total	161	112%

#### Invitation to cancer clinical trials 147 Responses

Q27 - Have you ever been invited to participate in a cancer clinical trial?

	Count ▲	Percent
No	116	79%
Yes	22	15%
Don't know of any clinical trials in my country	7	5%
Don't know / can't remember	2	1%
Total	147	100%

#### Invitation to cancer clinical trials - Positive Score 145 Responses

Q27+ - Have you ever been invited to participate in a cancer clinical trial?

	Count ▲	Percent
No	116	80%
Yes	22	15%
I do not know of any clinical trials in my country	7	5%

#### Actually participated 52 Responses

Q28 - Did you agree to participate in the cancer clinical trial?

	Count ▲	Percent
Yes	25	48%
No	20	38%
DK / CR	7	13%
Total	52	100%

#### Actually participated - Positive Score 45 Responses

Q28+ - Did you agree to participate in the cancer clinical trial?

	Count ▲	Percent
Yes	25	56%
No	20	44%
Total	45	100%



### Cancer clinical trials

#### Reasons for participation 25 Responses

Q29 - Why did you agree to participate? (PLEASE CHOOSE ALL THAT APPLY)

Count ▲ Percent

My doctor recommended it	15	60%
I wanted to help kidney cancer research	13	52%
Affordability, financial reasons	12	48%
I thought it might offer better care	11	44%
I wanted a specific type of treatment	4	16%
Other	3	12%
Don't know / Can't remember	1	4%
Total	59	236%

#### Satisfaction with overall experience of clinical trial 25 Responses

Q30 - How satisfied were you overall with your cancer clinical trial experience?

Count ▲ Percent

Neither satisfied nor dissatisfied	13	52%
Very satisfied	8	32%
Satisfied	4	16%
Total	25	100%

#### Potential participation 124 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	47	38%
Neither likely nor unlikely	37	30%
Very likely	27	22%
Very unlikely	9	7%
Unlikely	4	3%
Total	124	100%

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

Thinking about my health status... 141 Responses

Q32 - I feel in blackout - I feel on alert - I am aware - I feel positive	Count ▲	Percent
I feel on the alert	47	33%
I am aware	33	23%
I feel positive	29	21%
I am aware/I feel positive	10	7%
I feel on the alert/I am aware	8	6%
I feel in blackout/I feel on the alert	7	5%
I feel in blackout	7	5%
Total	141	100%

Thinking about my health status... 142 Responses

Q33 - I feel dazed - I am in alarm - I am conscious - I feel serene	Count ▲	Percent
I am conscious	80	56%
I feel serene	24	17%
I am in alarm	11	8%
I am conscious/I feel serene	9	6%
I am in alarm/I am conscious	8	6%
I feel dazed/I am in alarm	6	4%
I feel dazed	4	3%
Total	142	100%

Thinking about my health status... 142 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	47	33%
Despite my illness I perceive coherence and continuity in my life	35	25%
I have got used to my illness condition	23	16%
When I think about my illness I feel overwhelmed by emotions	11	8%
Anxious every time a new symptom arises/I have got used to my illness condition	11	8%
I have got used to my illness condition/Despite my illness I perceive coherence and continuity in my life	9	6%
I feel overwhelmed by emotions/anxious every time a new symptom arises	6	4%
Total	142	100%

Thinking about my health status... 140 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	41	29%
I feel anxious when I try to manage my illness	25	18%
I am generally optimist about my future and my health condition	22	16%
I feel anxious when I try to manage my illness/I feel I have adjusted to my illness	19	14%
I feel very discouraged due to my illness	13	9%
I feel I have adjusted to my illness/I am generally optimist about my future and my health condition	13	9%
I feel very discouraged due to my illness/I feel anxious when I try to manage my illness	7	5%
Total	140	100%

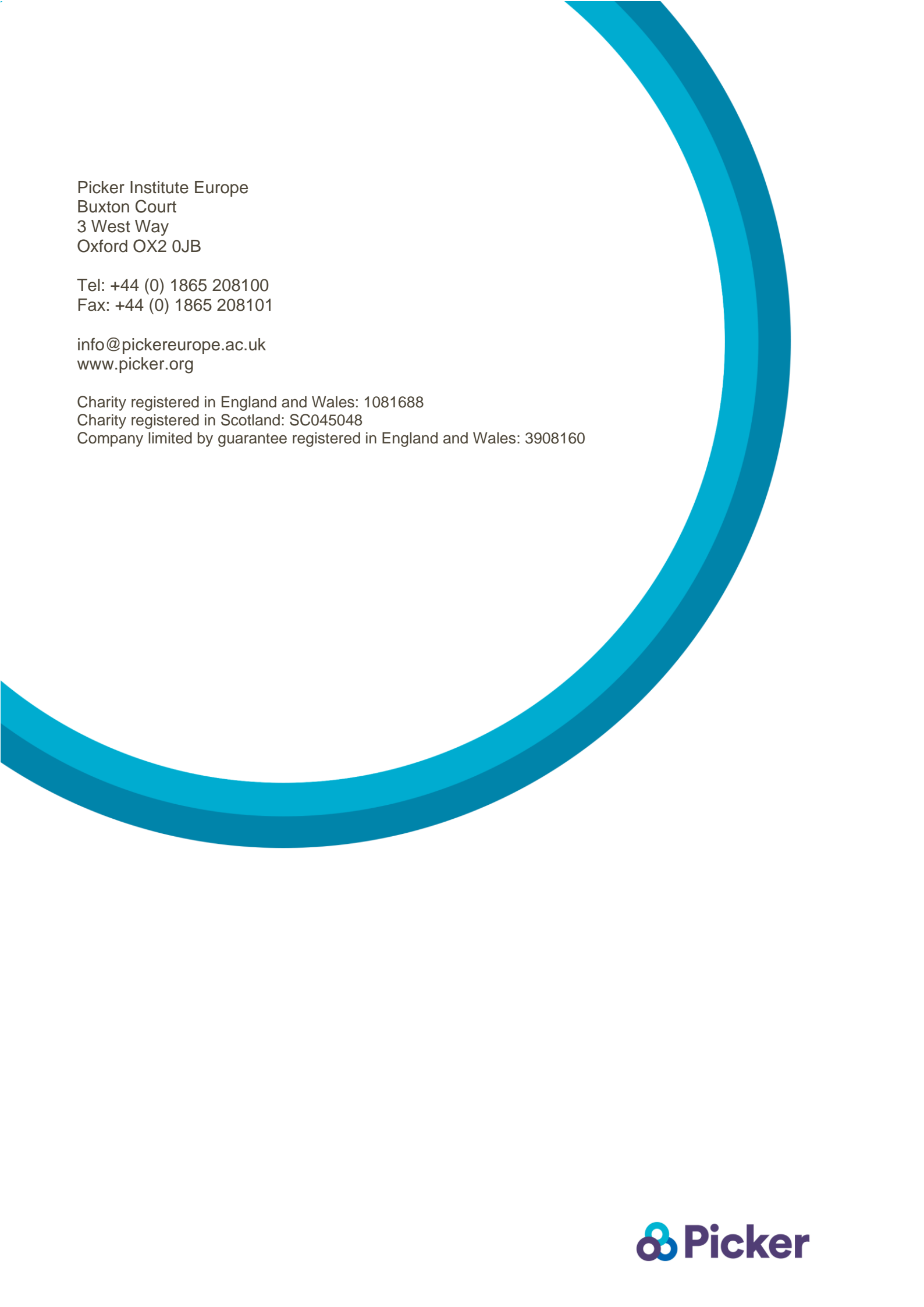
### Patient Health Engagement scale from the Università Cattolica del Sacro Cuore

Thinking about my health status... 141 Responses

Q36 - I feel totally oppress - I am upset - I have accepted - I have sense

Count ▲ Percent

I am upset when a new symptom arises	51	36%
I feel I have accepted my illness	30	21%
I can give sense to my life despite my illness condition	29	21%
I am upset when a new symptom arises/I feel I have accepted my illness	11	8%
I feel totally oppressed by my illness	9	6%
I feel I have accepted my illness/I can give sense to my life despite my illness condition	6	4%
I feel totally oppressed by my illness/I am upset when a new symptom arises	5	4%
Total	141	100%

A large, stylized blue circular graphic that is partially visible on the left and top edges of the page, composed of concentric arcs in different shades of blue.

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