



# International Kidney Cancer Coalition Global Survey 2020

Canada 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

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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## 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 **241** respondents from Canada. Comprised of:

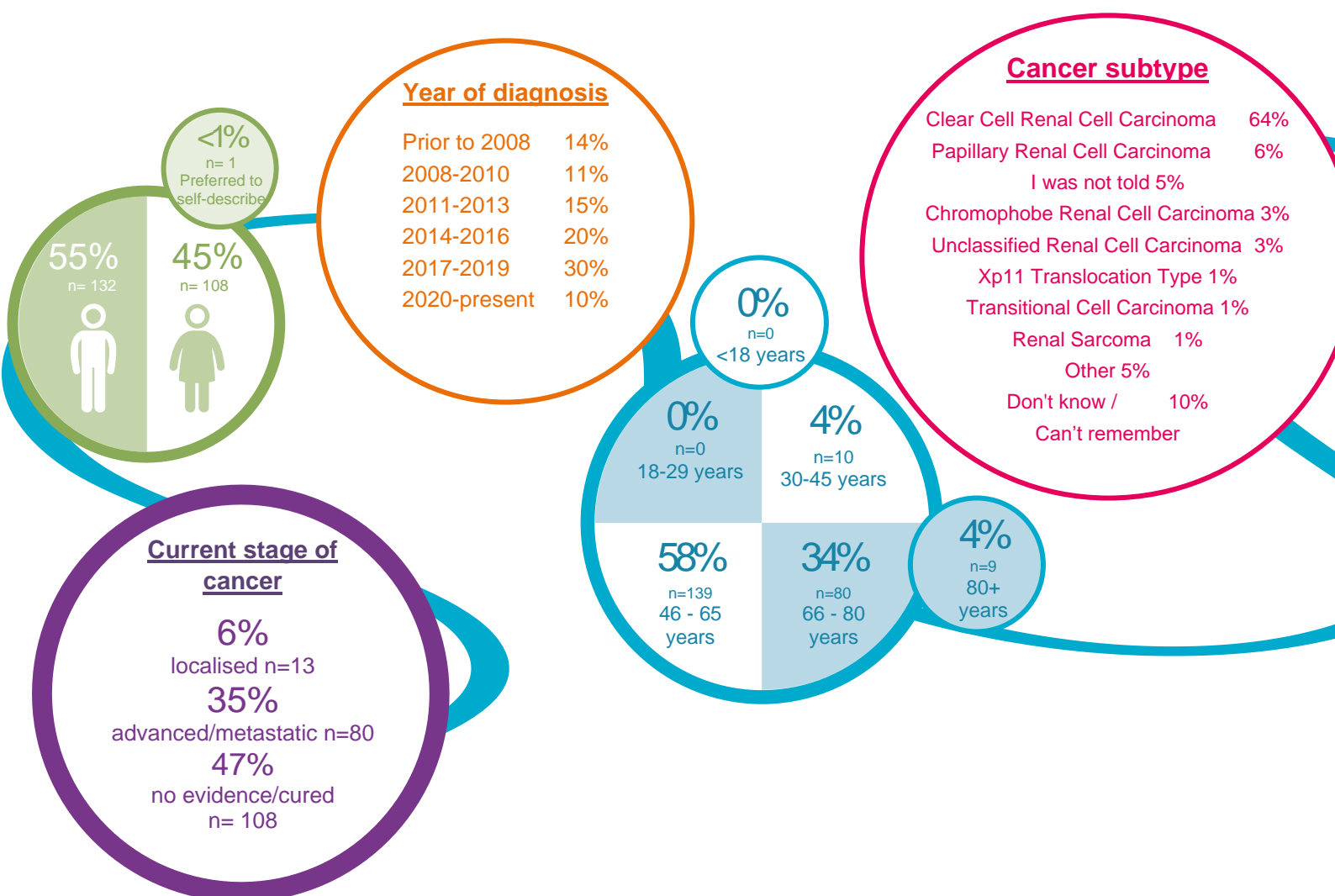


**205** patients



**34** carers or caregivers

**2** undisclosed



## Key results

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

Time to diagnosis – see page 6



**70%** 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



**64%** 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



**89%** of respondents completely or to some extent understood 'treatment options', at diagnosis

**92%** felt that 'treatment recommendations' were completely/to some extent understood at diagnosis

**37%** reported that the likelihood of surviving their cancer beyond five years was not explained

Barriers to treatment – see page 8



**41%** of respondents reported experiencing barriers to treatment

Biopsy – see page 8



**48%** of respondents had a biopsy (35% of the kidney; 13% of other sites)

**4%** 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



**48%** of respondents indicated that “No one” discussed cancer clinical trials with them.

### Experience of clinical trials – see page 9



**34%** 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

**11%** were dissatisfied with their clinical trial experience

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

### Level of physical activity – see page 10



**45%** of respondents self-reported that they were insufficiently active or completely sedentary

### Psychosocial wellbeing – see page 10



**48%** of respondents indicated that they ‘very often’ or ‘always’ experienced a fear of recurrence

**39%** of respondents indicated that they ‘very often’ or ‘always’ experienced disease-related anxiety

**31%** of respondents indicated that they ‘very often’ or ‘always’ experienced general anxiety

### Seeking support – see page 11



**53%** of respondents reported having talked to their doctor / healthcare professional about their concerns

## Summary of results – Canada

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 – Canada.

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

10% (n=25) of respondents from Canada received a diagnosis in the year prior to taking to the survey (between 2020 and 2021). 30% (n=71) of respondents received a diagnosis between 2017 and 2019, whereas 60% (n=144) received a diagnosis in 2016 or prior<sup>4</sup>.

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

26% (n=61) of respondents who were residents of Canada 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 Canada 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 Canada, 44% (n=99) 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. 57% (n=121) of respondents in Canada indicated that this was the case.

At diagnosis (Canada respondents):

- 80% (n=186) completely or to some extent understood 'stage of cancer' (Globally this was 85%, n=1576)
- 89% (n=197) completely or to some extent understood 'treatment options' (Globally this was 88%, n=1603)
- 92% (n=203) felt that 'treatment recommendations' were completely/to some extent understood (Globally 88%, n=1569)
- 34% (n=72) said that cancer subtype was not explained (Globally 34%, n=587)
- 35% (n=74) said that risk of recurrence was not explained (Globally 31%, n=550)
- 37% (n=80) 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, 29% (n=68) of respondents in Canada reported ever having received a second opinion (globally 38%, n=733). 59% (n=139) reported that they decided not to get a second opinion (globally 51%, n=982). Whereas 4% (n=10) said that this was not an option to them (globally 4%, n=75) and 8% (n=19) 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 Canada, this accounted for 64% (n=149) 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

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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.

Canada, 59% (n=140) indicated that this was the case. In addition, 12% (n=28) indicated that their friends/other family members were involved.

22% (n=51) consulted their family doctor and 15% (n=35) used online resources.

### **Barriers to treatment**

59% of respondents (n=138) reported experiencing no barriers to treatment, relative to 44% (n=839) globally. The most commonly experienced barriers reported from respondents in Canada were:

- Wait time to treatment – 35% of respondents (n=33)
- Other barrier – 24% (n=23)
- No speciality doctor locally – 22% (n=21)
- Lack of personal support – 17% (n=16)
- No access to up-to-date treatment or equipment – 16% (n=15)

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

At the time of completing the survey, 47% (n=108) of respondents in Canada indicated that they had no evidence of disease / were cured. 6% (n=13) of respondents noted that their tumour was still only within the kidney (stage 1 or 2). Whereas 35% (n=80) of respondents indicated that their cancer was advanced/metastasised.

### **Biopsy practice**

Overall, 48% (n=109) of respondents in Canada had a biopsy, 35% (n=79) of a kidney growth and 13% (n=30) 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, 32% (n=73) of respondents in Canada indicated that their tissue was looked at after they had surgery to remove it. Globally, this was 36% (n=664) of respondents. A further 16% (n=35) reported that they were never offered a biopsy – 17% (n=314) globally while 4% (n=8) were offered a biopsy but refused the procedure (3%, n=47 globally).

Of the respondents in Canada who did not have a biopsy, 64% (n=72) 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 Canada, over 60% of respondents agreed/strongly agreed that they understood the following:

- surgical options (90%, n=197 of respondents, globally 90%, n=1637)
- active surveillance (83%, n=169 of respondents, globally 75%, n=1272)
- the role of nutrition/lifestyle on their wellbeing (79%, n=175 of respondents, globally 78%, n=1393)
- local guidelines for kidney care follow-up (70%, n=148 of respondents, globally 64%, n=1081)
- palliative care (64%, n=114 of respondents, globally 65%, n=985)
- targeted therapy options (62%, n=117 of respondents, globally 71%, n=1140)

In Canada, more than one in five respondents disagreed/strongly disagreed that they understood the following:

- ablative therapy options (25%, n=46 of respondents, globally 19%, n=293)
- complementary therapies (e.g. meditation, etc.) (23%, n=46 of respondents, globally 16%, n=272)

## 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

48% of respondents in Canada (n=109) indicated that no one spoke to them about cancer clinical trials. Of those that did discuss cancer clinical trials, 22% (n=25) indicated that clinical trials had been discussed with a patient organisation/support group, and 80% (n=93) said with a doctor/nurse.

### Taking part in clinical trial

34% (n=76) of respondents who were residents of Canada were invited to participate in a cancer clinical trial (compared with 31% (n=549) globally). 64% (n=69) of respondents

indicated that they participated in a cancer clinical trial and 67% (n=44) reported being satisfied with their overall experience. 11% (n=7) were dissatisfied.

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 (69%, n=104) reported that it was very likely or likely they would participate.

## 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.

45% of respondents in Canada (n=100) self-reported that they were insufficiently active/completely sedentary. This is compared with 46% of respondents globally (n=830). 38% of respondents (n=85) reported physical levels to be within guidelines (150-299 minutes of physical activity per week) while 17% (n=39) described their level of physical activity as above guidelines of more than 300 minutes per week.

### Psychosocial wellbeing

Overall, respondents from Canada reported high levels of emotional wellbeing relative to global data.

Below are the areas which were of most concern to respondents:

- 48% (n=107) said that they very often/always had the fear of recurrence, 55% (n=1003) globally
- 39% (n=88) reported that they very often/always felt disease-specific anxiety, compared with 49% (n=904) globally
- 31% (n=71) of respondents reported that they very often/always felt general anxiety, compared with 43% (n=792) globally
- 25% (n=56) reported that they very often/always experienced fear of dying, compared with 31% (n=563) globally

## Sources of support

53% (n=112) of respondents in Canada 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. 51% of respondents (n=115) reported that they had contacted a patient support group, compared with 64% (n=1179) of respondents globally.

Of those who had contacted a patient support group, 42% (n=48) 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 Canada, please see the Frequency Tables in Appendix 2.

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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.



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

- 1% (n=3) of respondents residing in Canada 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.*
- 21% (n=47) of respondents residing in Canada 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.*
- 45% (n=100) of respondents residing in Canada 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.*
- 33% (n=74) of respondents residing in Canada were classified as the 'Meaning and purpose – I am a person' state (globally 22%, n=403)  
*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 Canada 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 – Canada
2. Frequency Tables – Canada
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

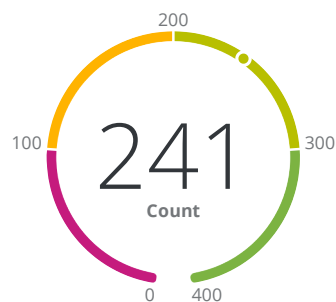
*Country specific reports where respondent numbers are greater or equal to 100. These include:*

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

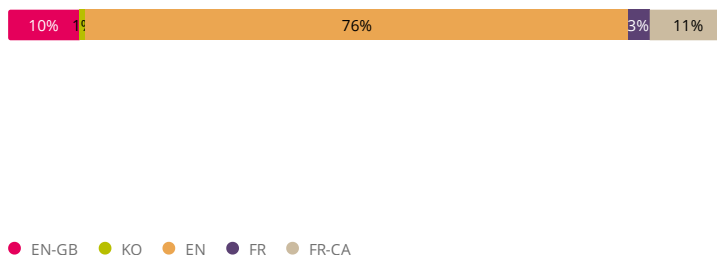


## About the respondents

Response count

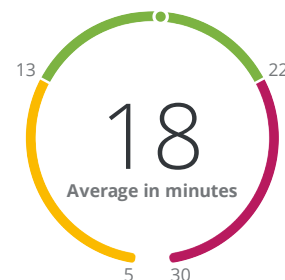


Responses per language 241 Responses

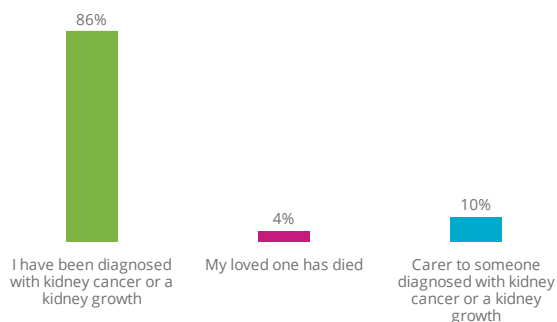


Average of minutes per response

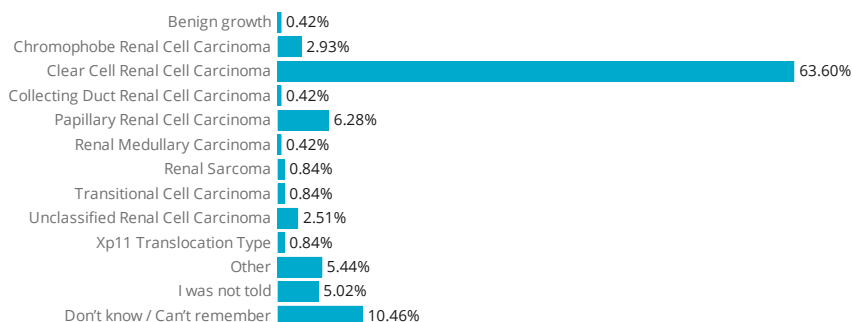
237 Responses



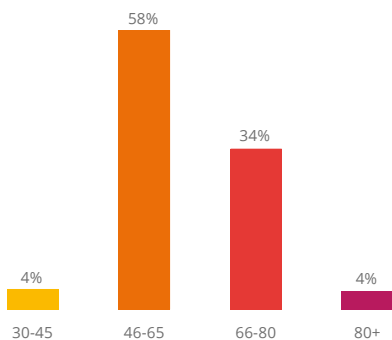
Described experience with kidney cancer 239 Responses



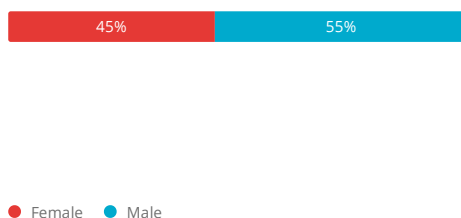
Sub-type of kidney cancer 239 Responses



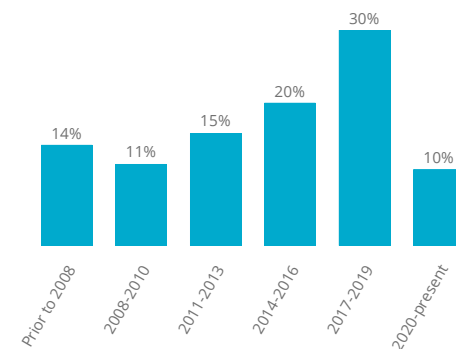
Age 238 Responses



Gender 241 Responses

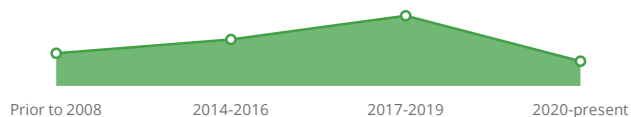


Diagnosis Year 240 Responses



### Diagnosis

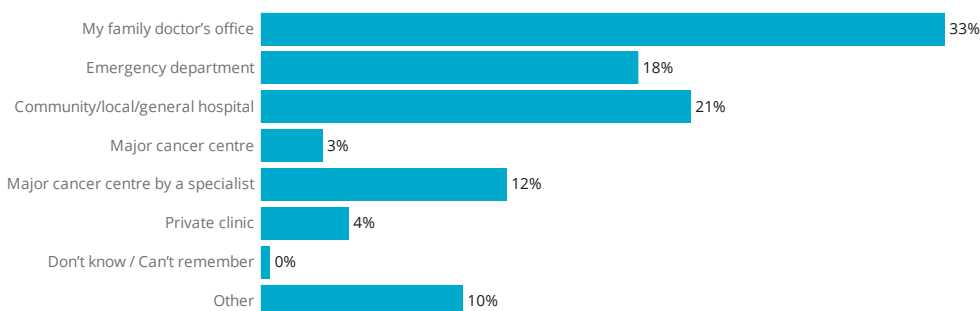
Diagnosis Year 240 Responses



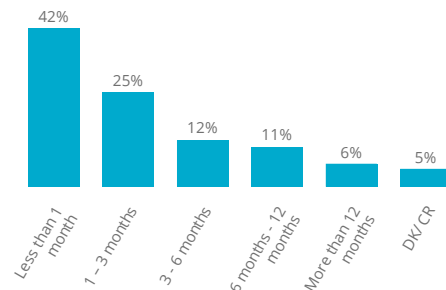
When first diagnosed were you told what subtype? 239 Responses



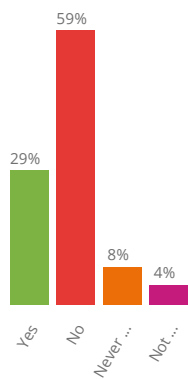
First correctly diagnosed 239 Responses



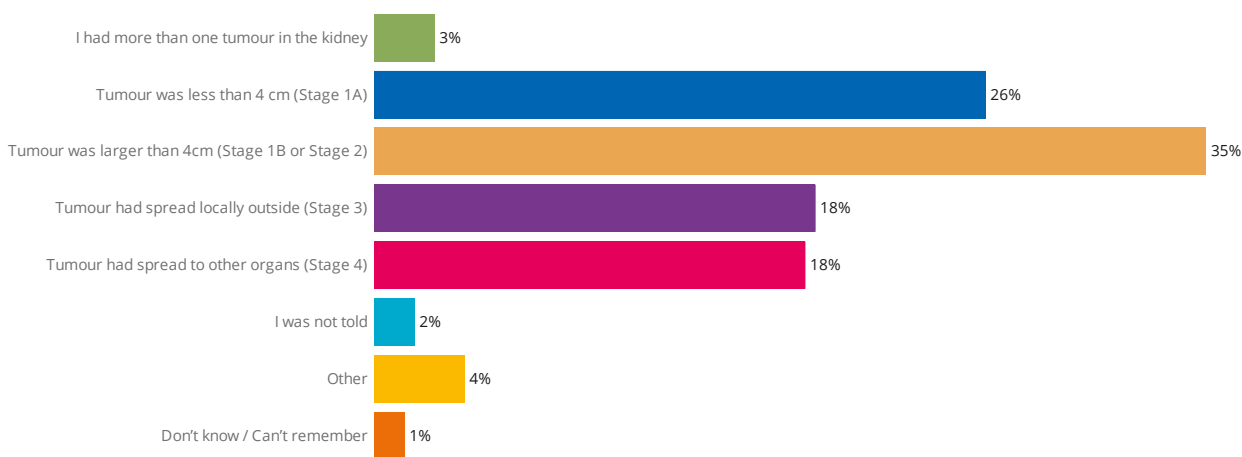
How long was it from the time you first thought something might be wrong with you to being CORRECTLY diagnosed? 237 Responses



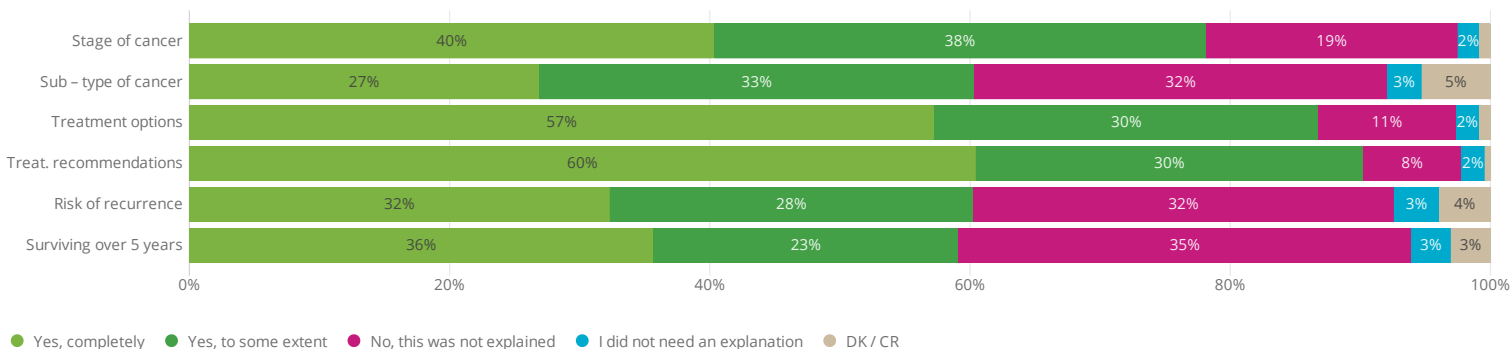
Did you ever seek a second opinion with a kidney cancer expert? 236 Responses



What stage when first diagnosed? 238 Responses

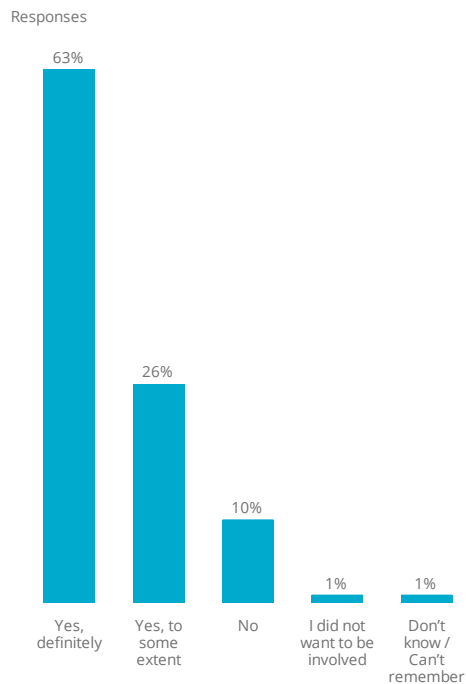


AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? 238 Responses

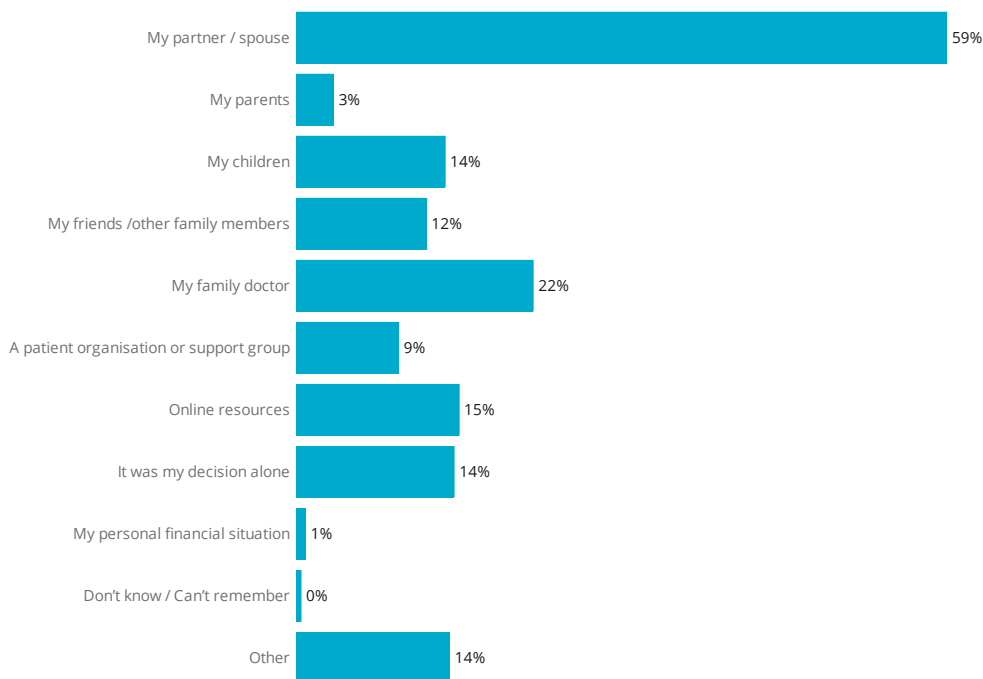


## Developing a treatment plan

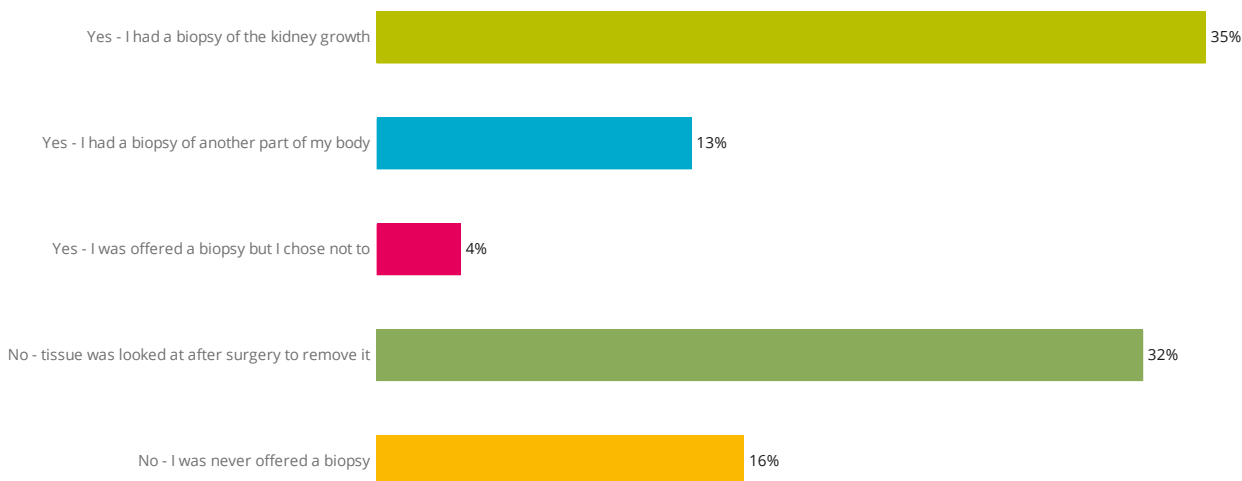
Were you involved as much as you wanted to be in decisions about your treatment plan? 237 Responses



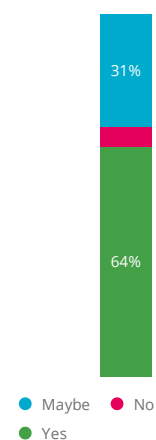
Who or what else helped you make decisions about your treatment plan? 237 Responses



Have you ever been offered a biopsy of some part of your body where kidney cancer was thought to be? 225 Responses



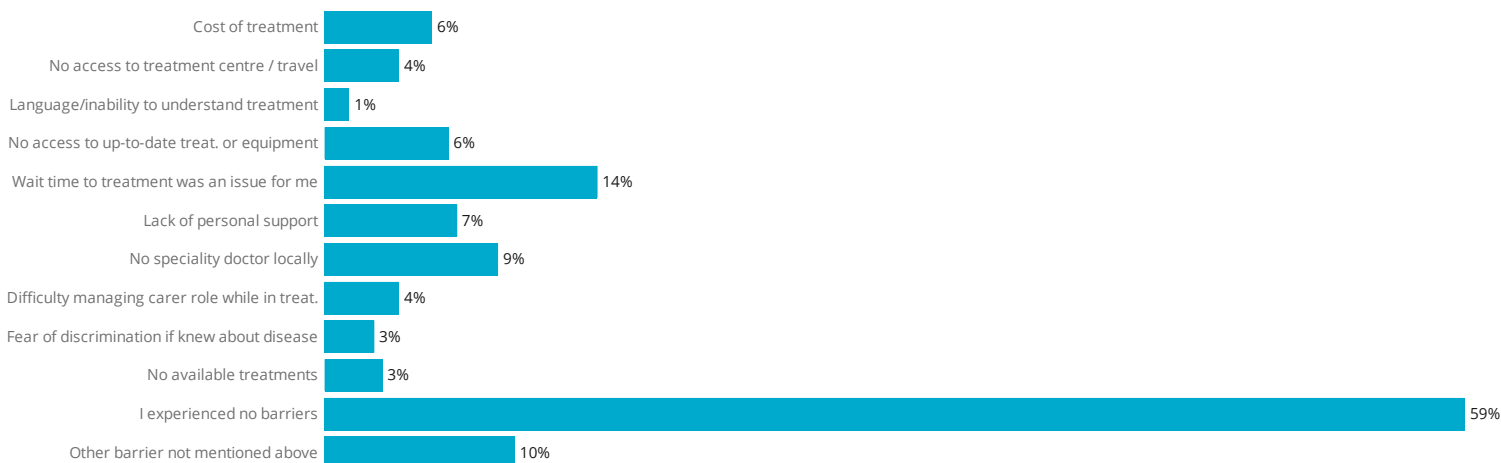
Would you be willing to have a biopsy in the future if necessary? 113 Responses



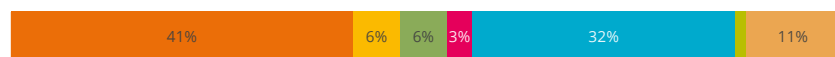
● Maybe ● No ● Yes

### Your care and treatment & your care today

Which barriers (if any) have you experienced in receiving treatment for your kidney cancer or kidney growth? 232 Responses

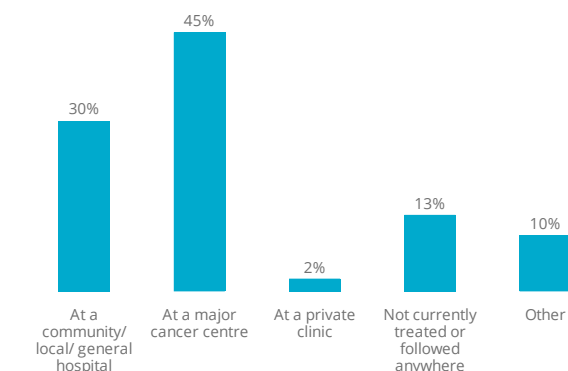


Which of the following best describes your stage of kidney cancer or kidney growth TODAY? 230 Responses

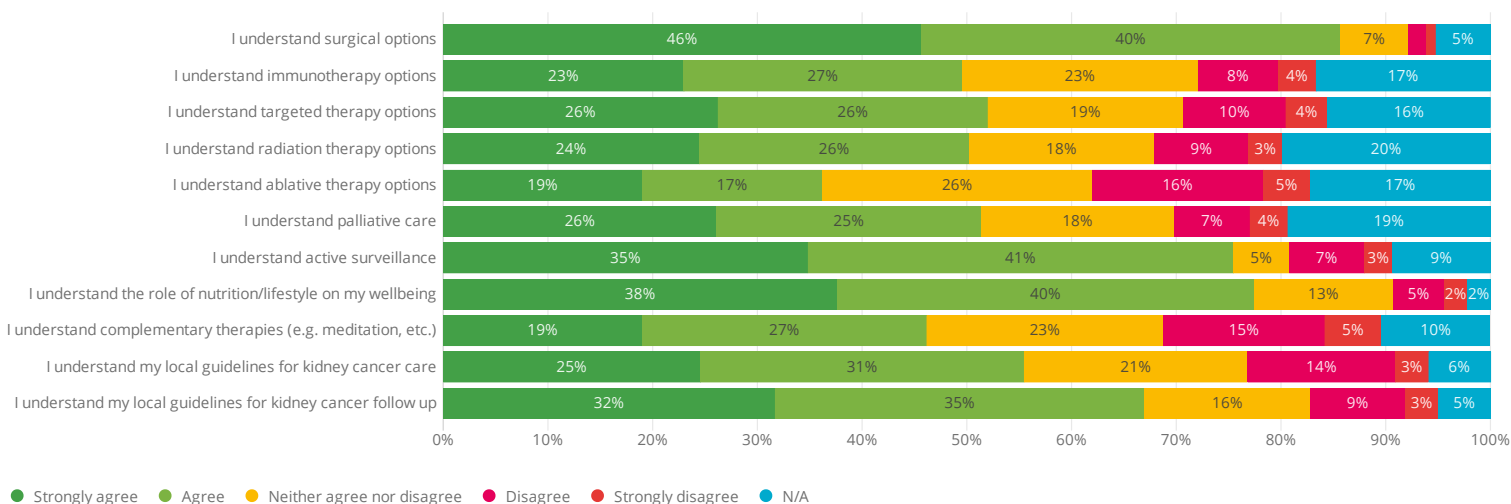


- I currently have no evidence of disease
- I was told that I am cured
- Kidney cancer / growth is still only within the kidney (Stage 1 or Stage 2)
- Kidney cancer / growth is still locally advanced (Stage 3)
- Kidney cancer / growth has spread to other organs or distant sites (Stage 4)
- Don't know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

Where are you CURRENTLY being treated or followed? 226 Responses

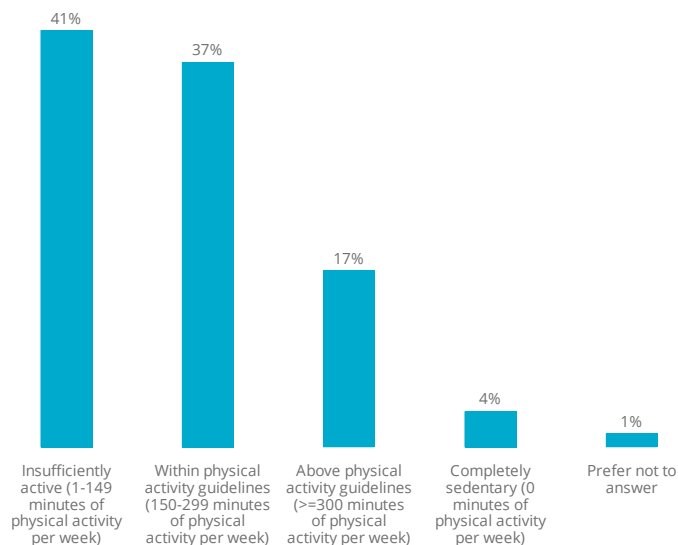


To what extent do you agree or disagree with the following statements?

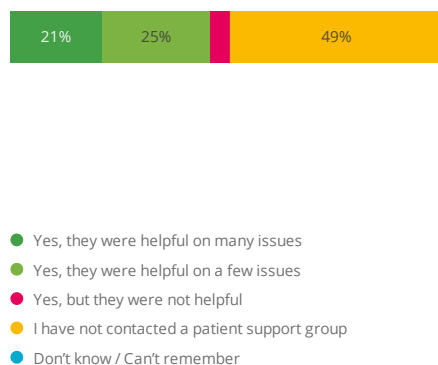


### Quality of life

Current level of leisure-time physical activity 227 Responses



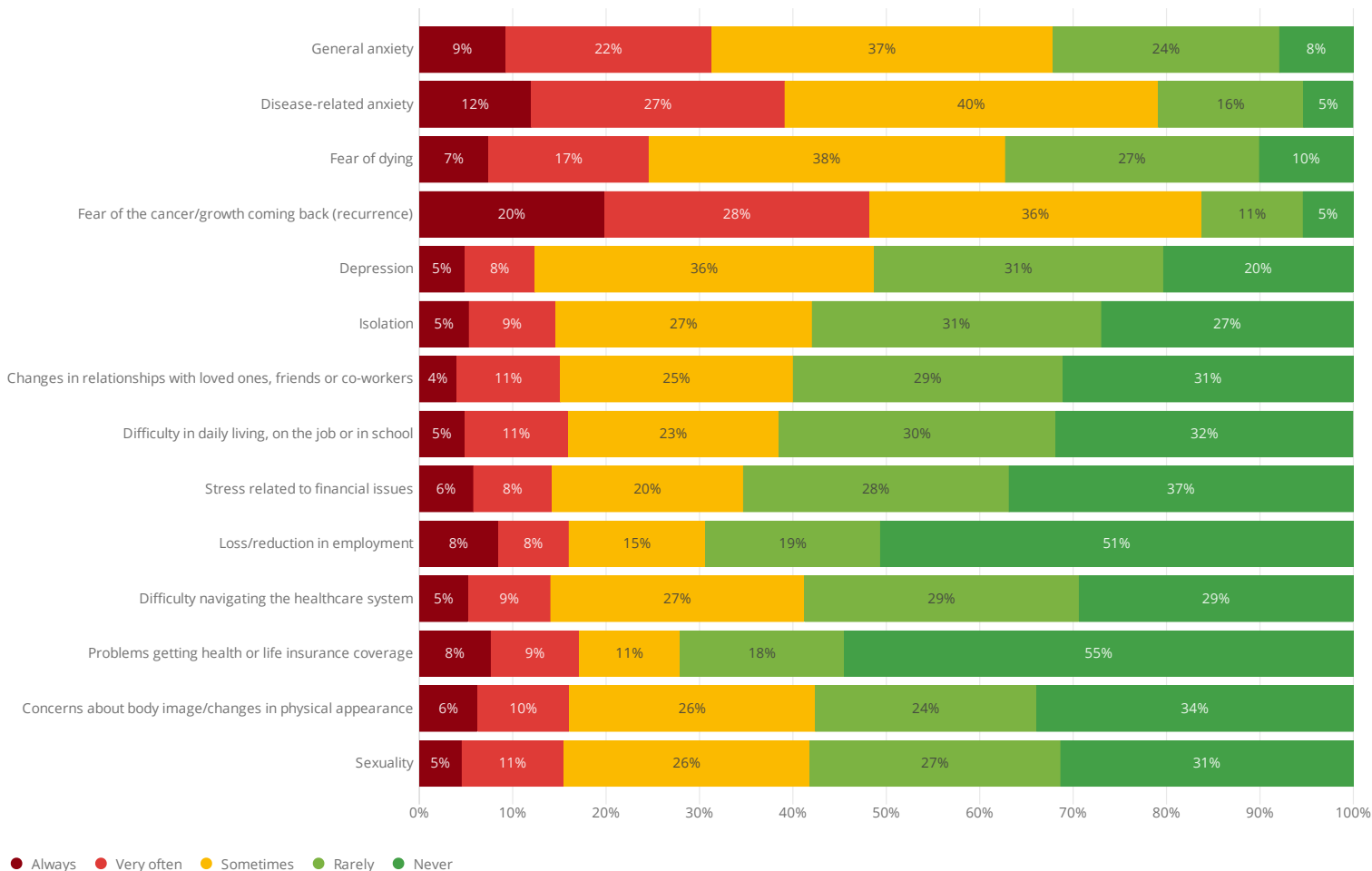
Have you ever used a patient support group (either in person or online) to help you with your kidney cancer / growth? 230 Responses



Have you ever talked to your doctor or to any other healthcare professional about any of these concerns? 216 Responses

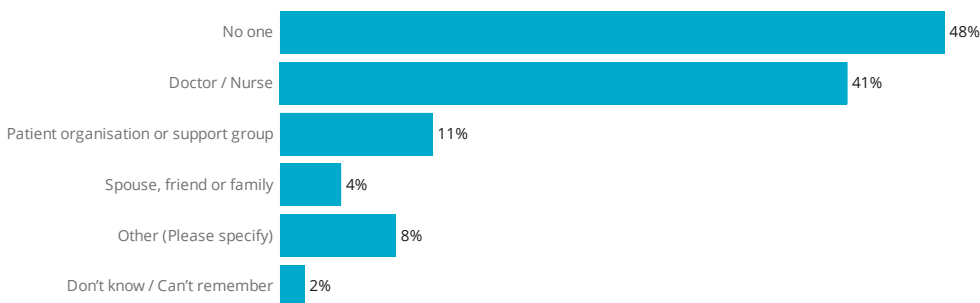


How often have the following impacted your sense of emotional well-being since your diagnosis?

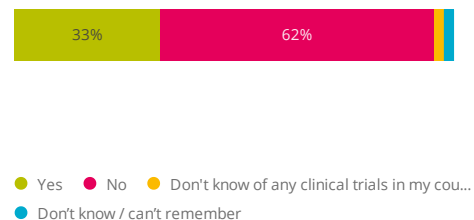


## Cancer clinical trials

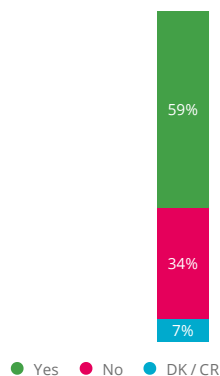
Who, if anyone, has discussed cancer clinical trials with you? 229 Responses



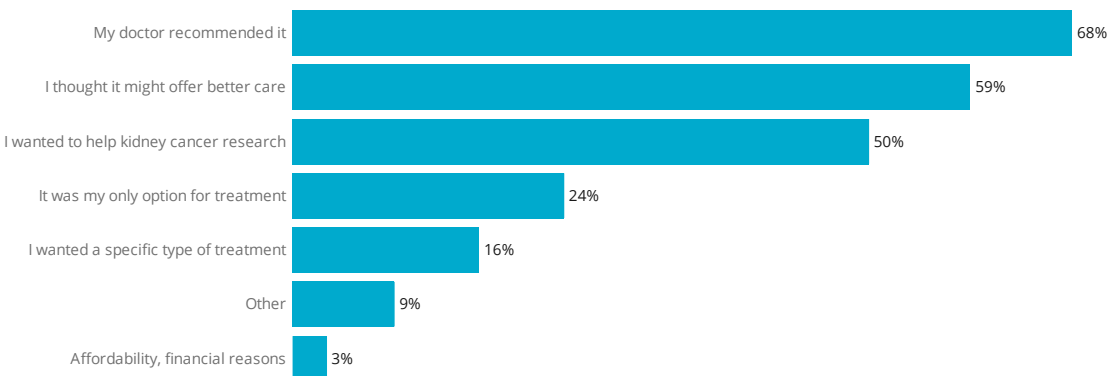
Have you ever been invited to participate in a cancer clinical trial? 229 Responses



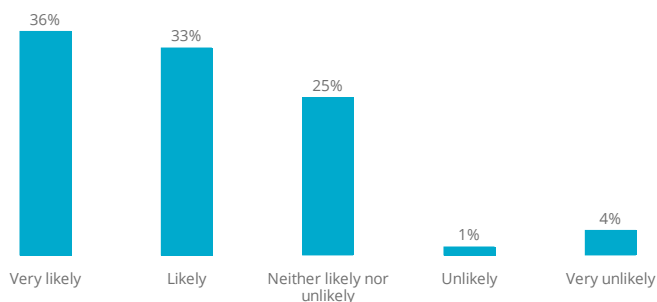
Did you agree to participate in the cancer clinical trial? 116 Responses



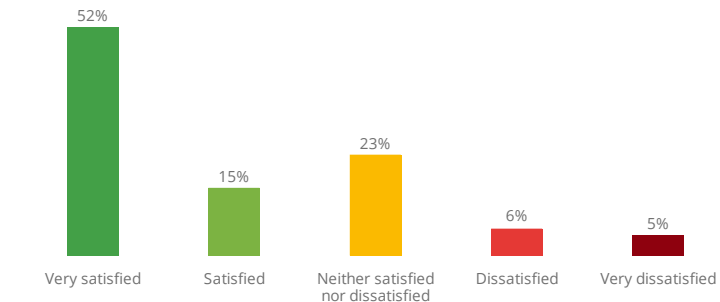
Why did you agree to participate? 68 Responses



If you had been or were invited, how likely is it that you would participate in a cancer clinical trial? 150 Responses



How satisfied were you overall with your cancer clinical trial experience? 66 Responses



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

Thinking about my health status... 223 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... 221 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... 220 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... 218 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... 216 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 239 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	205	86%
I am a carer or caregiver to someone who has been diagnosed with kidney cancer or a kidney growth	24	10%
My loved one has died	10	4%
Total	239	100%

### Sub-type of kidney cancer 239 Responses

Q2 - What sub-type of kidney cancer do you have?	Count ▲	Percent
Clear Cell Renal Cell Carcinoma	152	64%
Don't know / Can't remember	25	10%
Papillary Renal Cell Carcinoma	15	6%
Other	13	5%
I was not told	12	5%
Chromophobe Renal Cell Carcinoma	7	3%
Unclassified Renal Cell Carcinoma	6	3%
Xp11 Translocation Type	2	1%
Transitional Cell Carcinoma (Urothelial Carcinoma)	2	1%
Renal Sarcoma (NOT Renal Cell Carcinoma with Sarcomatoid Appearance)	2	1%
Renal Medullary Carcinoma	1	0%
Collecting Duct Renal Cell Carcinoma (Bellini Duct)	1	0%
Benign growth	1	0%
Total	239	100%

### Country of residence 241 Responses

Q3 - List of Countries	Count	Percent
<a href="#">Canada</a>	241	100%
Total	241	100%

### Age 238 Responses

Q4 - What is your age now?	Count ▲	Percent
46-65	139	58%
66-80	80	34%
30-45	10	4%
80+	9	4%
Total	238	100%

### Gender 241 Responses

Q5 - What is your gender?	Count ▲	Percent
Male	132	55%
Female	108	45%
I prefer to self describe	1	0%
Total	241	100%



### Diagnosis

Diagnosis Year 240 Responses

Q6 - In what year were you diagnosed?	Count ▲	Percent
2017-2019	71	30%
2014-2016	47	20%
2011-2013	37	15%
Prior to 2008	33	14%
2008-2010	27	11%
2020-present	25	10%
Total	240	100%

When first diagnosed were you told what subtype? 239 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	121	51%
Yes	93	39%
Not sure	25	10%
Total	239	100%

What stage when first diagnosed? 238 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)	83	35%
Tumour was less than 4 cm (Stage 1A)	61	26%
Tumour had spread locally outside (Stage 3)	44	18%
Tumour had spread to other organs (Stage 4)	43	18%
Other	9	4%
I had more than one tumour in the kidney	6	3%
I was not told	4	2%
Don't know / Can't remember	3	1%
Total	253	106%

First correctly diagnosed 239 Responses

Q7 - Where was your kidney growth FIRST CORRECTLY DIAGNOSED?	Count ▲	Percent
My family doctor's office	78	33%
Community/local/general hospital	49	21%
Emergency department	43	18%
Major cancer centre by a specialist	28	12%
Other	23	10%
Private clinic	10	4%
Major cancer centre	7	3%
Don't know / Can't remember	1	0%
Total	239	100%

When first diagnosed were you told what subtype? - Positive Score 214 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	121	57%
Yes	93	43%
Total	214	100%

### Diagnosis

#### How long to correct diagnosis? 237 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	99	42%
1 – 3 months	59	25%
3 - 6 months	29	12%
6 months - 12 months	25	11%
More than 12 months	14	6%
DK/ CR	11	5%
Total	237	100%

#### How long to correct diagnosis? - Positive Score 226 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	99	44%
1 – 3 months	59	26%
3 - 6 months	29	13%
6 months - 12 months	25	11%
More than 12 months	14	6%
Total	226	100%

#### Explanation at diagnosis - Stage of cancer 238 Responses

Q11a - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Stage of cancer	Count ▲	Percent
Yes, completely	96	40%
Yes, to some extent	90	38%
No, this was not explained	46	19%
I did not need an explanation	4	2%
Don't know / can't remember	2	1%
Total	238	100%

#### Explanation at diagnosis - Stage of cancer - Positive Score 232 Responses

Q11a+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Stage of cancer	Count ▲	Percent
Yes, completely	96	41%
Yes, to some extent	90	39%
No, this was not explained	46	20%
Total	232	100%

#### Explanation at diagnosis - Subtype of cancer 227 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	76	33%
No, this was not explained	72	32%
Yes, completely	61	27%
Don't know / can't remember	12	5%
I did not need an explanation	6	3%
Total	227	100%

#### Explanation at diagnosis - Subtype of cancer - Positive Score 209 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	76	36%
No, this was not explained	72	34%
Yes, completely	61	29%
Total	209	100%

### Diagnosis

Explanation at diagnosis - Treatment options 227 Responses

Q11c - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment options	Count ▲	Percent
Yes, completely	130	57%
Yes, to some extent	67	30%
No, this was not explained	24	11%
I did not need an explanation	4	2%
Don't know / can't remember	2	1%
Total	227	100%

Explanation at diagnosis - Treatment options - Positive Score 221 Responses

Q11c+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment options	Count ▲	Percent
Yes, completely	130	59%
Yes, to some extent	67	30%
No, this was not explained	24	11%
Total	221	100%

Explanation at diagnosis - Treatment recommendations 225 Responses

Q11d - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment recommendations	Count ▲	Percent
Yes, completely	136	60%
Yes, to some extent	67	30%
No, this was not explained	17	8%
I did not need an explanation	4	2%
Don't know / can't remember	1	0%
Total	225	100%

Explanation at diagnosis - Treatment recommendations - Positive Score

220 Responses

Q11d+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment recommendations	Count ▲	Percent
Yes, completely	136	62%
Yes, to some extent	67	30%
No, this was not explained	17	8%
Total	220	100%

Explanation at diagnosis - Risk of recurrence 229 Responses

Q11e - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Risk of recurrence	Count ▲	Percent
Yes, completely	74	32%
No, this was not explained	74	32%
Yes, to some extent	64	28%
Don't know / can't remember	9	4%
I did not need an explanation	8	3%
Total	229	100%

Explanation at diagnosis - Risk of recurrence - Positive Score 212 Responses

Q11e+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Risk of recurrence	Count ▲	Percent
Yes, completely	74	35%
No, this was not explained	74	35%
Yes, to some extent	64	30%
Total	212	100%

## Diagnosis

### Explanation at diagnosis - Likelihood of surviving beyond 5 yrs 230 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

Yes, completely	82	36%
No, this was not explained	80	35%
Yes, to some extent	54	23%
I did not need an explanation	7	3%
Don't know / can't remember	7	3%
Total	230	100%

### Explanation at diagnosis - Likelihood of surviving beyond 5 yrs - Positive Score 216 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

Yes, completely	82	38%
No, this was not explained	80	37%
Yes, to some extent	54	25%
Total	216	100%

### Second opinion 236 Responses

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

Count ▲ Percent

No	139	59%
Yes	68	29%
Never considered it	19	8%
Not available to me	10	4%
Total	236	100%

## Developing a treatment plan

### Involvement in treatment plan 237 Responses

Q13 - Were you involved as much as you wanted to be in decisions about your treatment plan?	Count ▲	Percent
Yes, definitely	149	63%
Yes, to some extent	61	26%
No	23	10%
I did not want to be involved	2	1%
Don't know / Can't remember	2	1%
Total	237	100%

### Involvement in treatment plan - Positive Score 233 Responses

Q13+ - Were you involved as much as you wanted to be in decisions about your treatment plan?	Count ▲	Percent
Yes, definitely	149	64%
Yes, to some extent	61	26%
No	23	10%
Total	233	100%

### Support in treatment plan decisions 237 Responses

Q14 - Who or what else helped you make decisions about your treatment plan? (PLEASE CHOOSE ALL THAT APPLY)	Count ▲	Percent
My partner / spouse	140	59%
My family doctor	51	22%
Online resources	35	15%
It was my decision alone	34	14%
Other	33	14%
My children	32	14%
My friends /other family members	28	12%
A patient organisation or support group	22	9%
My parents	8	3%
My personal financial situation	2	1%
Don't know / Can't remember	1	0%
Total	386	163%

### Barriers to treatment 232 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	138	59%
Wait time to treatment was an issue for me	33	14%
Other barrier not mentioned above	23	10%
No speciality doctor locally	21	9%
Lack of personal support	16	7%
No access to up-to-date treat. or equipment	15	6%
Cost of treatment	13	6%
No access to treatment centre / travel	9	4%
Difficulty managing carer role while in treat.	9	4%
No available treatments	7	3%
Fear of discrimination if knew about disease	6	3%
Language/inability to understand treatment	3	1%
Total	293	126%

## Your care and treatment & your care today

### Stage of kidney cancer or kidney growth TODAY 230 Responses

Q16 - Which of the following best describes your stage of kidney cancer or kidney growth TODAY?	Count ▲	Percent
I currently have no evidence of disease	95	41%
Kidney cancer / growth has spread to other organs or distant sites (Stage 4)	73	32%
Other (Please specify)	26	11%
Kidney cancer / growth is still only within the kidney (Stage 1 or Stage 2)	13	6%
I was told that I am cured	13	6%
Kidney cancer / growth is still locally advanced (Stage 3)	7	3%
Don't know / Can't remember	3	1%
Total	230	100%

### Understanding of care/treatment - Surgical options 230 Responses

Q18a - I understand surgical options	Count ▲	Percent
Strongly agree	105	46%
Agree	92	40%
Neither agree nor disagree	15	7%
N/A	12	5%
Disagree	4	2%
Strongly disagree	2	1%
Total	230	100%

### Understanding of care/treatment - Immunotherapy options 222 Responses

Q18b - I understand immunotherapy options	Count ▲	Percent
Agree	59	27%
Strongly agree	51	23%
Neither agree nor disagree	50	23%
N/A	37	17%
Disagree	17	8%
Strongly disagree	8	4%
Total	222	100%

### Treatment TODAY 226 Responses

Q17 - Where are you CURRENTLY being treated or followed?	Count ▲	Percent
At a major cancer centre	102	45%
At a community/ local/ general hospital	67	30%
Not currently treated or followed anywhere	30	13%
Other	22	10%
At a private clinic	5	2%
Total	226	100%

### Understanding of care/treatment - Surgical options - Positive Score 218 Responses

Q18a+ - I understand surgical options	Count ▲	Percent
Strongly agree	105	48%
Agree	92	42%
Neither agree nor disagree	15	7%
Disagree	4	2%
Strongly disagree	2	1%
Total	218	100%

### Understanding of care/treatment - Immunotherapy options - Positive Score 185 Responses

Q18b+ - I understand immunotherapy options	Count ▲	Percent
Agree	59	32%
Strongly agree	51	28%
Neither agree nor disagree	50	27%
Disagree	17	9%
Strongly disagree	8	4%
Total	185	100%

### Your care and treatment & your care today

#### Understanding of care/treatment - Targeted therapy options 225 Responses

Q18c - I understand targeted therapy options	Count ▲	Percent
Strongly agree	59	26%
Agree	58	26%
Neither agree nor disagree	42	19%
N/A	35	16%
Disagree	22	10%
Strongly disagree	9	4%
Total	225	100%

#### Understanding of care/treatment - Targeted therapy options - Positive Score 190 Responses

Q18c+ -I understand targeted therapy options	Count ▲	Percent
Strongly agree	59	31%
Agree	58	31%
Neither agree nor disagree	42	22%
Disagree	22	12%
Strongly disagree	9	5%
Total	190	100%

#### Understanding of care/treatment - Radiation therapy options 221 Responses

Q18d - I understand radiation therapy options	Count ▲	Percent
Agree	57	26%
Strongly agree	54	24%
N/A	44	20%
Neither agree nor disagree	39	18%
Disagree	20	9%
Strongly disagree	7	3%
Total	221	100%

#### Understanding of care/treatment - Radiation therapy options - Positive Score 177 Responses

Q18d+ - I understand radiation therapy options	Count ▲	Percent
Agree	57	32%
Strongly agree	54	31%
Neither agree nor disagree	39	22%
Disagree	20	11%
Strongly disagree	7	4%
Total	177	100%

#### Understanding of care/treatment - Ablative therapy options 221 Responses

Q18e - I understand ablative therapy options	Count ▲	Percent
Neither agree nor disagree	57	26%
Strongly agree	42	19%
N/A	38	17%
Agree	38	17%
Disagree	36	16%
Strongly disagree	10	5%
Total	221	100%

#### Understanding of care/treatment - Ablative therapy options - Positive Score 183 Responses

Q18e+ - I understand ablative therapy options	Count ▲	Percent
Neither agree nor disagree	57	31%
Strongly agree	42	23%
Agree	38	21%
Disagree	36	20%
Strongly disagree	10	5%
Total	183	100%

### Your care and treatment & your care today

#### Understanding of care/treatment - Palliative 222 Responses

Q18f - I understand palliative care	Count ▲	Percent
Strongly agree	58	26%
Agree	56	25%
N/A	43	19%
Neither agree nor disagree	41	18%
Disagree	16	7%
Strongly disagree	8	4%
Total	222	100%

#### Understanding of care/treatment - Palliative - Positive Score 179 Responses

Q18f+ - I understand palliative care	Count ▲	Percent
Strongly agree	58	32%
Agree	56	31%
Neither agree nor disagree	41	23%
Disagree	16	9%
Strongly disagree	8	4%
Total	179	100%

#### Understanding of care/treatment - Active Surveillance 224 Responses

Q18g - I understand active surveillance	Count ▲	Percent
Agree	91	41%
Strongly agree	78	35%
N/A	21	9%
Disagree	16	7%
Neither agree nor disagree	12	5%
Strongly disagree	6	3%
Total	224	100%

#### Understanding of care/treatment - Active Surveillance - Positive Score 203 Responses

Q18g+ - I understand active surveillance	Count ▲	Percent
Agree	91	45%
Strongly agree	78	38%
Disagree	16	8%
Neither agree nor disagree	12	6%
Strongly disagree	6	3%
Total	203	100%

#### Understanding of care/treatment - Role of nutrition/lifestyle 226 Responses

Q18h - I understand the role of nutrition/lifestyle on my wellbeing	Count ▲	Percent
Agree	90	40%
Strongly agree	85	38%
Neither agree nor disagree	30	13%
Disagree	11	5%
Strongly disagree	5	2%
N/A	5	2%
Total	226	100%

#### Understanding of care/treatment - Role of nutrition/lifestyle - Positive Score 221 Responses

Q18h+ - I understand the role of nutrition/lifestyle on my wellbeing	Count ▲	Percent
Agree	90	41%
Strongly agree	85	38%
Neither agree nor disagree	30	14%
Disagree	11	5%
Strongly disagree	5	2%
Total	221	100%



### Your care and treatment & your care today

#### Understanding of care/treatment - Complementary therapies 221 Responses

Q18i - I understand complementary therapies (e.g. meditation, etc.)	Count ▲	Percent
Agree	60	27%
Neither agree nor disagree	50	23%
Strongly agree	42	19%
Disagree	34	15%
N/A	23	10%
Strongly disagree	12	5%
Total	221	100%

#### Understanding of care/treatment - Complementary therapies - Positive Score 198 Responses

Q18i+ - I understand complementary therapies (e.g. meditation, etc.)	Count ▲	Percent
Agree	60	30%
Neither agree nor disagree	50	25%
Strongly agree	42	21%
Disagree	34	17%
Strongly disagree	12	6%
Total	198	100%

#### Understanding of care/treatment - Local guidelines for care 220 Responses

Q18j - I understand my local guidelines for kidney cancer care	Count ▲	Percent
Agree	68	31%
Strongly agree	54	25%
Neither agree nor disagree	47	21%
Disagree	31	14%
N/A	13	6%
Strongly disagree	7	3%
Total	220	100%

#### Understanding of care/treatment - Local guidelines for care - Positive Score 207 Responses

Q18j+ - I understand my local guidelines for kidney cancer care	Count ▲	Percent
Agree	68	33%
Strongly agree	54	26%
Neither agree nor disagree	47	23%
Disagree	31	15%
Strongly disagree	7	3%
Total	207	100%

#### Understanding of care/treatment - Local guidelines for follow up 221 Responses

Q18k - I understand my local guidelines for kidney cancer follow up	Count ▲	Percent
Agree	78	35%
Strongly agree	70	32%
Neither agree nor disagree	35	16%
Disagree	20	9%
N/A	11	5%
Strongly disagree	7	3%
Total	221	100%

#### Understanding of care/treatment - Local guidelines for follow up - Positive Score 210 Responses

Q18k+ - I understand my local guidelines for kidney cancer follow up	Count ▲	Percent
Agree	78	37%
Strongly agree	70	33%
Neither agree nor disagree	35	17%
Disagree	20	10%
Strongly disagree	7	3%
Total	210	100%

## Your care and treatment & your care today

### Biopsy experience 225 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

Yes - I had a biopsy of the kidney growth	79	35%
No - tissue was looked at after surgery to remove it	73	32%
No - I was never offered a biopsy	35	16%
Yes - I had a biopsy of another part of my body	30	13%
Yes - I was offered a biopsy but I chose not to	8	4%
Total	225	100%

### Biopsy 113 Responses

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

Count ▲ Percent

Yes	72	64%
Maybe	35	31%
No	6	5%
Total	113	100%

### Quality of life

#### Physical activity 227 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

Insufficiently active (1-149 minutes of physical activity per week)	92	41%
Within physical activity guidelines (150-299 minutes of physical activity per week)	85	37%
Above physical activity guidelines ( $\geq 300$ minutes of physical activity per week)	39	17%
Completely sedentary (0 minutes of physical activity per week)	8	4%
Prefer not to answer.	3	1%
Total	227	100%

#### Physical activity - Positive Score 224 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

Insufficiently active (1-149 minutes of physical activity per week)	92	41%
Within physical activity guidelines (150-299 minutes of physical activity per week)	85	38%
Above physical activity guidelines ( $\geq 300$ minutes of physical activity per week)	39	17%
Completely sedentary (0 minutes of physical activity per week)	8	4%
Total	224	100%

#### Emotional well-being - General anxiety 227 Responses

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

Count ▲ Percent

Sometimes	83	37%
Rarely	55	24%
Very often	50	22%
Always	21	9%
Never	18	8%
Total	227	100%

#### Emotional well-being - Disease related anxiety 225 Responses

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

Count ▲ Percent

Sometimes	90	40%
Very often	61	27%
Rarely	35	16%
Always	27	12%
Never	12	5%
Total	225	100%

#### Emotional well-being - Fear of dying 228 Responses

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

Count ▲ Percent

Sometimes	87	38%
Rarely	62	27%
Very often	39	17%
Never	23	10%
Always	17	7%
Total	228	100%

#### Emotional well-being - Fear of cancer/growth coming back 222 Responses

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

Count ▲ Percent

Sometimes	79	36%
Very often	63	28%
Always	44	20%
Rarely	24	11%
Never	12	5%
Total	222	100%

### Quality of life

#### Emotional well-being - Depression 226 Responses

Q22e - How often have the following impacted your sense of emotional well-being since your diagnosis?

Count ▲ Percent

Sometimes	82	36%
Rarely	70	31%
Never	46	20%
Very often	17	8%
Always	11	5%
Total	226	100%

#### Emotional well-being - Isolation 226 Responses

Q22f - How often have the following impacted your sense of emotional well-being since your diagnosis?

Count ▲ Percent

Rarely	70	31%
Sometimes	62	27%
Never	61	27%
Very often	21	9%
Always	12	5%
Total	226	100%

#### Emotional well-being - Changes in relationships 225 Responses

Q22g - How often have the following impacted your sense of emotional well-being since your diagnosis?

Count ▲ Percent

Never	70	31%
Rarely	65	29%
Sometimes	56	25%
Very often	25	11%
Always	9	4%
Total	225	100%

#### Emotional well-being - Difficulty in daily living 226 Responses

Q22h - How often have the following impacted your sense of emotional well-being since your diagnosis?

Count ▲ Percent

Never	72	32%
Rarely	67	30%
Sometimes	51	23%
Very often	25	11%
Always	11	5%
Total	226	100%

#### Emotional well-being - Stress related to financial issues 225 Responses

Q22i - How often have the following impacted your sense of emotional well-being since your diagnosis?

Count ▲ Percent

Never	83	37%
Rarely	64	28%
Sometimes	46	20%
Very often	19	8%
Always	13	6%
Total	225	100%

#### Emotional well-being - Loss/reduction in employment 225 Responses

Q22j - How often have the following impacted your sense of emotional well-being since your diagnosis?

Count ▲ Percent

Never	114	51%
Rarely	42	19%
Sometimes	33	15%
Always	19	8%
Very often	17	8%
Total	225	100%

### Quality of life

#### Emotional well-being - Difficulty navigating the healthcare system 228

Responses

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

Count ▲ Percent

Rarely	67	29%
Never	67	29%
Sometimes	62	27%
Very often	20	9%
Always	12	5%
Total	228	100%

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

222 Responses

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

Count ▲ Percent

Never	121	55%
Rarely	39	18%
Sometimes	24	11%
Very often	21	9%
Always	17	8%
Total	222	100%

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

224 Responses

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

Count ▲ Percent

Never	76	34%
Sometimes	59	26%
Rarely	53	24%
Very often	22	10%
Always	14	6%
Total	224	100%

#### Emotional well-being - Sexuality 220 Responses

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

Count ▲ Percent

Never	69	31%
Rarely	59	27%
Sometimes	58	26%
Very often	24	11%
Always	10	5%
Total	220	100%

## Quality of life

### Seeking support from medical professional 216 Responses

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

Count ▲ Percent

Yes	112	52%
No	99	46%
Don't know / Can't remember	5	2%
Total	216	100%

### Seeking support from medical professional - Positive Score 211 Responses

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

Count ▲ Percent

Yes	112	53%
No	99	47%
Total	211	100%

### Seeking support from PSG 230 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	112	49%
Yes, they were helpful on a few issues	57	25%
Yes, they were helpful on many issues	48	21%
Yes, but they were not helpful	10	4%
Don't know / Can't remember	3	1%
Total	230	100%

### Seeking support from PSG - Positive Score 227 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	112	49%
Yes, they were helpful on a few issues	57	25%
Yes, they were helpful on many issues	48	21%
Yes, but they were not helpful	10	4%
Total	227	100%

## Cancer clinical trials

### Discussion with whom 229 Responses

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

	Count ▲	Percent
No one	109	48%
Doctor / Nurse	93	41%
Patient organisation or support group	25	11%
Other (Please specify)	19	8%
Spouse, friend or family	10	4%
Don't know / Can't remember	4	2%
Total	260	114%

### Invitation to cancer clinical trials 229 Responses

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

	Count ▲	Percent
No	143	62%
Yes	76	33%
Don't know of any clinical trials in my country	5	2%
Don't know / can't remember	5	2%
Total	229	100%

### Invitation to cancer clinical trials - Positive Score 224 Responses

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

	Count ▲	Percent
No	143	64%
Yes	76	34%
I do not know of any clinical trials in my country	5	2%
Total	224	100%

### Actually participated 116 Responses

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

	Count ▲	Percent
Yes	69	59%
No	39	34%
DK / CR	8	7%
Total	116	100%

### Actually participated - Positive Score 108 Responses

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

	Count ▲	Percent
Yes	69	64%
No	39	36%
Total	108	100%

## Cancer clinical trials

### Reasons for participation 68 Responses

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

Count ▲ Percent

My doctor recommended it	46	68%
I thought it might offer better care	40	59%
I wanted to help kidney cancer research	34	50%
It was my only option for treatment	16	24%
I wanted a specific type of treatment	11	16%
Other	6	9%
Affordability, financial reasons	2	3%
Total	155	228%

### Satisfaction with overall experience of clinical trial 66 Responses

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

Count ▲ Percent

Very satisfied	34	52%
Neither satisfied nor dissatisfied	15	23%
Satisfied	10	15%
Dissatisfied	4	6%
Very dissatisfied	3	5%
Total	66	100%

### Potential participation 150 Responses

Q31 - If you had been or were invited, how likely is it that you would participate in a cancer clinical trial?

Count ▲ Percent

Very likely	54	36%
Likely	50	33%
Neither likely nor unlikely	38	25%
Very unlikely	6	4%
Unlikely	2	1%
Total	150	100%



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

Thinking about my health status... 223 Responses

Q32 - I feel in blackout - I feel on alert - I am aware - I feel positive	Count ▲	Percent
I am aware	88	39%
I feel positive	64	29%
I feel on the alert	38	17%
I am aware/I feel positive	21	9%
I feel on the alert/I am aware	7	3%
I feel in blackout/I feel on the alert	4	2%
I feel in blackout	1	0%
Total	223	100%

Thinking about my health status... 221 Responses

Q33 - I feel dazed - I am in alarm - I am conscious - I feel serene	Count ▲	Percent
I am conscious	114	52%
I am conscious/I feel serene	33	15%
I feel serene	31	14%
I am in alarm	20	9%
I am in alarm/I am conscious	16	7%
I feel dazed	5	2%
I feel dazed/I am in alarm	2	1%
Total	221	100%

Thinking about my health status... 220 Responses

Q34 - I am overwhelmed - I feel anxious - I am used - I perceive coherence	Count ▲	Percent
Despite my illness I perceive coherence and continuity in my life	80	36%
I feel anxious every time a new symptom arises	45	20%
I have got used to my illness condition	42	19%
Anxious every time a new symptom arises/I have got used to my illness condition	21	10%
I have got used to my illness condition/Despite my illness I perceive coherence and continuity in my life	18	8%
When I think about my illness I feel overwhelmed by emotions	10	5%
I feel overwhelmed by emotions/anxious every time a new symptom arises	4	2%
Total	220	100%

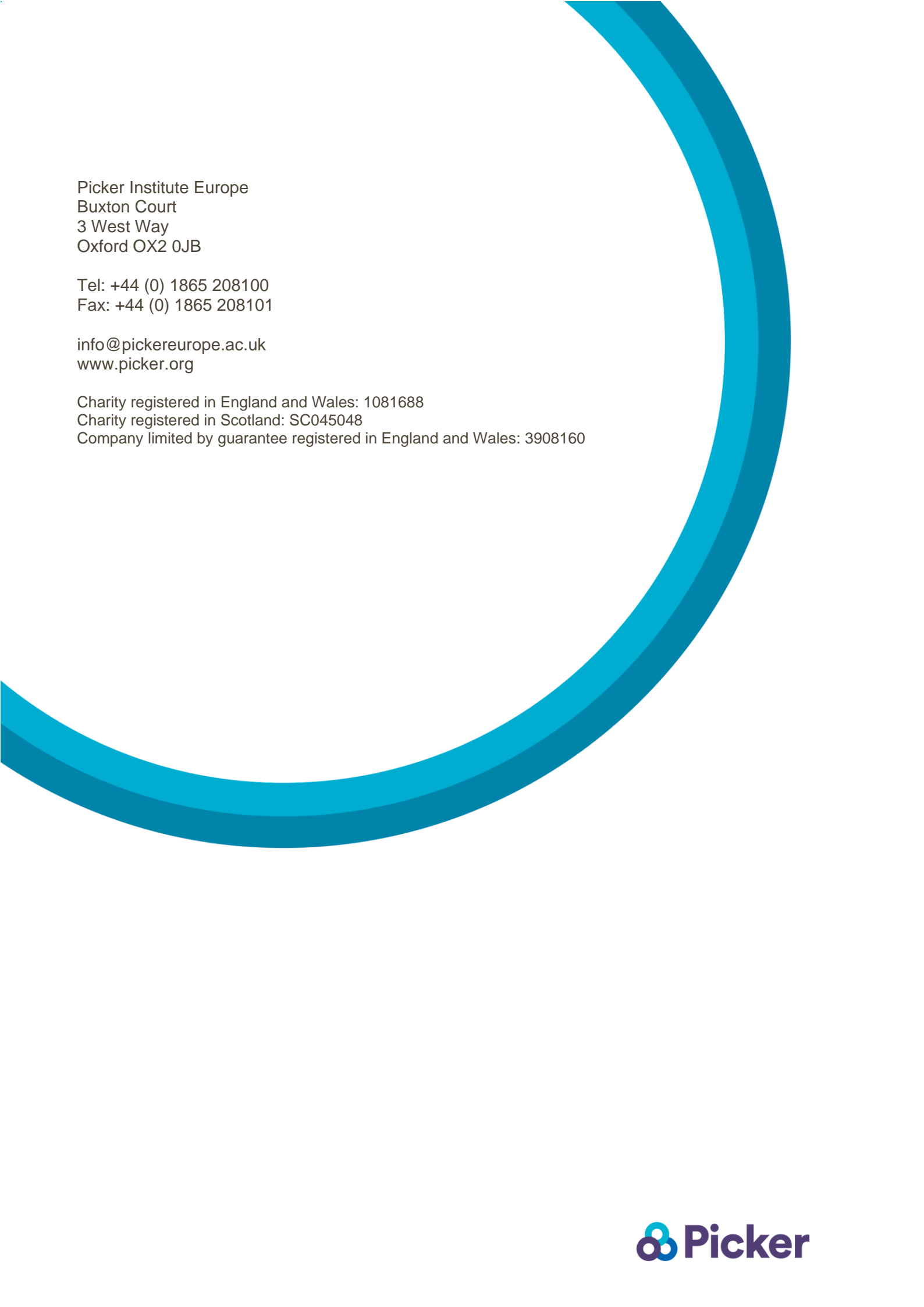
Thinking about my health status... 218 Responses

Q35 - I feel very discouraged - I feel anxious - I feel adjusted - I feel optimistic	Count ▲	Percent
I am generally optimist about my future and my health condition	89	41%
I feel I have adjusted to my illness	59	27%
I feel anxious when I try to manage my illness	22	10%
I feel I have adjusted to my illness/I am generally optimist about my future and my health condition	17	8%
I feel anxious when I try to manage my illness/I feel I have adjusted to my illness	13	6%
I feel very discouraged due to my illness	12	6%
I feel very discouraged due to my illness/I feel anxious when I try to manage my illness	6	3%
Total	218	100%

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

Thinking about my health status... 216 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	79	37%
I feel I have accepted my illness	50	23%
I am upset when a new symptom arises	35	16%
I am upset when a new symptom arises/I feel I have accepted my illness	23	11%
I feel I have accepted my illness/I can give sense to my life despite my illness condition	21	10%
I feel totally oppressed by my illness/I am upset when a new symptom arises	5	2%
I feel totally oppressed by my illness	3	1%
Total	216	100%

A large, thick blue circular graphic that is partially visible, with its top and bottom edges cut off by the page boundaries. It is composed of two concentric rings of different shades of blue.

Picker Institute Europe  
Buxton Court  
3 West Way  
Oxford OX2 0JB

Tel: +44 (0) 1865 208100  
Fax: +44 (0) 1865 208101

[info@pickereurope.ac.uk](mailto:info@pickereurope.ac.uk)  
[www.picker.org](http://www.picker.org)

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