International Kidney Cancer Coalition Global Survey 2020

France Country Report

July 2021

Prepared by: Picker for the

International Kidney Cancer Coalition

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.

Company Limited by Registered Guarantee No 3908160 | Registered Charity: 1081688 (England and Wales) SC045048 (Scotland) | Website: www.picker.org

Picker Institute Europe has UKAS accredited certification for ISO20252: 2012 (GB08/74322) and ISO27001:2013 (GB10/80275). We comply with Data Protection Laws including the General Data Protection Regulation, the Data Protection Act 2018 and the Market Research Society's (MRS) Code of Conduct.

Contents

Executive summary

Kidney cancer is a global issue. Every year, an estimated 431,000 people worldwide are diagnosed with the disease[1]. 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[2] (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[3] 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

---

[1] 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.

[2] **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.

[3] **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.

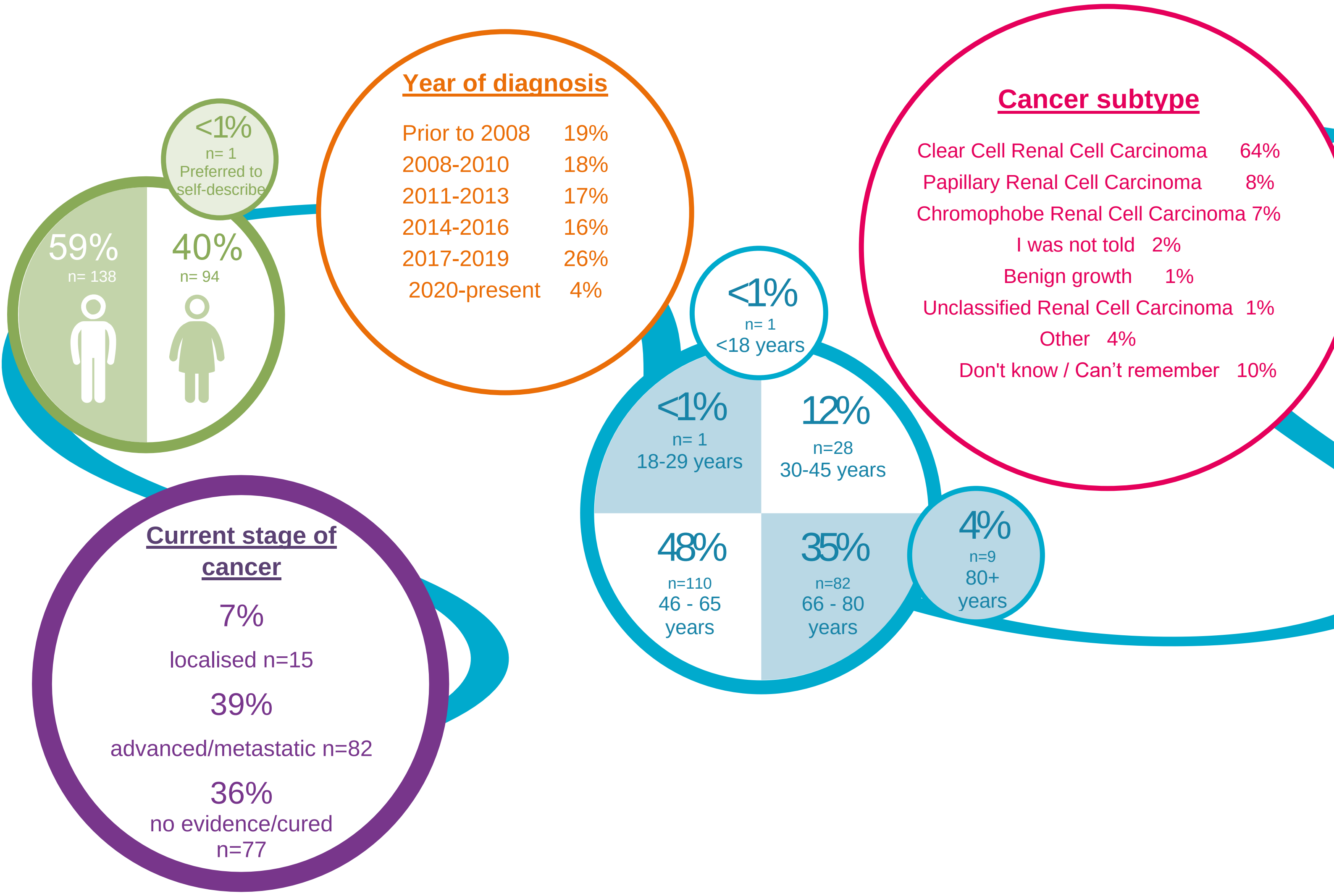
Survey activity

This report outlines the results from the **234** respondents from France. Comprised of:

200 patients

34 carers or caregivers

0 undisclosed



<1%
n= 1
Preferred to self-describe

59%
n= 138

40%
n= 94

Year of diagnosis

Prior to 2008	19%
2008-2010	18%
2011-2013	17%
2014-2016	16%
2017-2019	26%
2020-present	4%

<1%
n= 1
<18 years

<1%
n= 1
18-29 years

12%
n=28
30-45 years

48%
n=110
46 - 65 years

35%
n=82
66 - 80 years

4%
n=9
80+ years

Cancer subtype

Clear Cell Renal Cell Carcinoma	64%
Papillary Renal Cell Carcinoma	8%
Chromophobe Renal Cell Carcinoma	7%
I was not told	2%
Benign growth	1%
Unclassified Renal Cell Carcinoma	1%
Other	4%
Don't know / Can't remember	10%

Current stage of cancer

7%
localised n=15

39%
advanced/metastatic n=82

36%
no evidence/cured
n=77

Key results

Patient knowledge, expectations of treatment and shared decision making:

Time to diagnosis – see page 6

85% 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

50% 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

85% of respondents completely or to some extent understood ‘treatment options’, at diagnosis

81% felt that ‘treatment recommendations’ were completely/to some extent understood at diagnosis

43% reported that the likelihood of surviving their cancer beyond five years was not explained

Barriers to treatment – see page 8

24% of respondents reported experiencing barriers to treatment

Biopsy – see page 8

47% of respondents had a biopsy (37% of the kidney; 10% of other sites)

2% 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

40% of respondents indicated that “No one” discussed cancer clinical trials with them.

Experience of clinical trials – see page 9

38% of respondents were invited to take part in a clinical trial

58% of those who took part in a clinical trial were satisfied with their experience overall

10% were dissatisfied with their clinical trial experience

Quality of life and overall health status of respondents:

Level of physical activity – see page 10

47% of respondents self-reported that they were insufficiently active or completely sedentary

Psychosocial wellbeing – see page 10

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

46% of respondents indicated that they ‘very often’ or ‘always’ experienced disease-related anxiety

31% of respondents ‘very often’ or ‘always’ experienced general anxiety

31% of respondents ‘very often’ or ‘always’ experienced fear of dying

Seeking support – see page 11

61% of respondents reported having talked to their doctor / healthcare professional about their concerns

Summary of results – France

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

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

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

4% (n=10) of respondents from France received a diagnosis in the year prior to taking to the survey (between 2020 and 2021). 26% (n=59) of respondents received a diagnosis between 2017 and 2019, whereas 70% (n=162) received a diagnosis in 2016 or prior[4].

Stage of kidney tumour(s) at diagnosis

22% (n=50) of respondents who were residents of France 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.

0% (n=1) of respondents from France 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 France, 61% (n=135) of respondents reported receiving a diagnosis in under 1 month.

---

[4] 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%[5] (n=909) of respondents reported not being told what subtype of kidney cancer they had when they were first correctly diagnosed. 47% (n=102) of respondents in France indicated that this was the case.

At diagnosis (France respondents):

- 81% (n=179) completely or to some extent understood ‘stage of cancer’ (Globally this was 85%, n=1576)
- 85% (n=178) completely or to some extent understood ‘treatment options’ (Globally this was 88%, n=1603)
- 81% (n=160) felt that ‘treatment recommendations’ were completely/to some extent understood (Globally 88%, n=1569)
- 22% (n=43) said that cancer subtype was not explained (Globally 34%, n=587)
- 42% (n=83) said that risk of recurrence was not explained (Globally 31%, n=550)
- 43% (n=83) 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, 35% (n=80) of respondents in France reported ever having received a second opinion (globally 38%, n=733). 58% (n=131) reported that they decided not to get a second opinion (globally 51%, n=982). Whereas 0% (n=0) said that this was not an option to them (globally 4%, n=75) and 7% (n=15) 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 France, this accounted for 50% (n=113) 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

---

[5] 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.

France, 43% (n=97) indicated that this was the case. In addition, 7% (n=15) indicated that their friends/other family members were involved. However, 30% (n=67) indicated that it was their decision alone.

Barriers to treatment

76% of respondents (n=169) reported experiencing no barriers to treatment, relative to 44% (n=839) globally. The 5 most commonly experienced barriers reported from respondents in France were:

- Other barrier – 33% of respondents (n=18)
- No speciality doctor locally – 19% of respondents (n=10)
- Wait time to treatment – 17% of respondents (n=9)
- Lack of access to the most up-to-date treatment or equipment – 17% of respondents (n=9)
- Lack of personal support – 15% of respondents (n=8)

Stage of kidney tumour(s) today

At the time of completing the survey, 36% (n=77) of respondents in France indicated that they had no evidence of disease / were cured. 7% (n=15) of respondents noted that their tumour was still only within the kidney (stage 1 or 2). Whereas 39% (n=82) of respondents indicated that their cancer was advanced/metastasised.

Biopsy practice

Overall, 47% (n=101) of respondents in France had a biopsy, 37% (n=79) of a kidney growth and 10% (n=22) 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, 41% (n=87) of respondents in France indicated that their tissue was looked at after they had surgery to remove it. Globally, this was 36% (n=664) of respondents. A further 9% (n=20) reported that they were never offered a biopsy – 17% (n=314) globally while 2% (n=5) were offered a biopsy but refused the procedure (3%, n=47 globally).

Of the respondents in France who did not have a biopsy, 54% (n=64) 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 France, the majority of respondents agreed/strongly agreed that they understood the following:

- surgical options (95%, n=187 of respondents, globally 90%, n=1637)
- active surveillance (92%, n=166 of respondents, globally 75%, n=1272)
- immunotherapy options (89%, n=121 of respondents, globally 69%, n=1079)
- targeted therapy options (89%, n=120 of respondents, globally 71%, n=1140)
- radiation therapy options (84%, n=97 of respondents, globally 67%, n=1000)
- ablative therapy options (83%, n=124 of respondents, globally 56%, n=857)
- the role of nutrition/lifestyle on their wellbeing (79%, n=143 of respondents, globally 78%, n=1393)
- local guidelines for kidney cancer follow up (79%, n=139 of respondents, globally 69%, n=1203)
- palliative care (74%, n=85 of respondents, globally 69%, n=1203)
- local guidelines for kidney cancer care (68%, n=104 of respondents, globally 64%, n=1081)
- complementary therapies (60%, n=92 of respondents, globally 57%, n=949)

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

40% of respondents in France (n=84) indicated that no one spoke to them about cancer clinical trials. Of those that did discuss cancer clinical trials, 14% (n=17) indicated that clinical trials had been discussed with a patient organisation/support group, and 76% (n=91) said with a doctor/nurse.

Taking part in clinical trial

38% (n=80) of respondents who were residents of France were invited to participate in a cancer clinical trial, compared with 31% (n=549) globally. 66% (n=73) of respondents indicated that they participated in a cancer clinical trial and 58% (n=40) reported being satisfied with their overall experience. 10% (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 (64%, n=86) 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.

47% of respondents in France (n=95) self-reported that they were insufficiently active/completely sedentary. This is compared with 46% of respondents globally (n=830). 32% of respondents (n=65) reported physical levels to be within guidelines (150-299 minutes of physical activity per week) while 21% (n=43) described their level of physical activity as above guidelines of more than 300 minutes per week.

Psychosocial wellbeing

Overall, respondents from France reported high levels of emotional wellbeing relative to global data. Below are the areas which were of most concern to respondents:

- 55% (n=108) said that they very often/always had the fear of recurrence, 55% (n=1003) globally
- 46% (n=94) reported that they very often/always felt disease-specific anxiety, compared with 49% (n=904) globally
- 31% (n=62) of respondents reported that they very often/always felt general anxiety, compared with 43% (n=792) globally
- 31% (n=62) reported that they very often/always experienced fear of dying, compared with 31% (n=563) globally

Sources of support

61% (n=112) of respondents in France 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. 24% of respondents (n=50) 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, 18% (n=9) 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 Patent Health Engagement Scale (PHE-S) developed from the Patient Health Engagement Model[6] (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 France, please see the Frequency Tables in Appendix 2.

---

[6] 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 France: *(Definitions from Graffigna et al., 2015)*

- 2% (n=5) of respondents residing in France 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.

- 16% (n=33) of respondents residing in France 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.

- 53% (n=108) of respondents residing in France 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=57) of respondents residing in France 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 France 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 – France
2. Frequency Tables – France
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

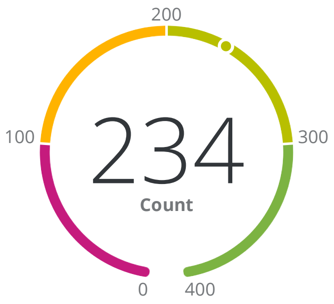
  Country specific reports where respondent numbers are greater or equal to 100. These include:

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

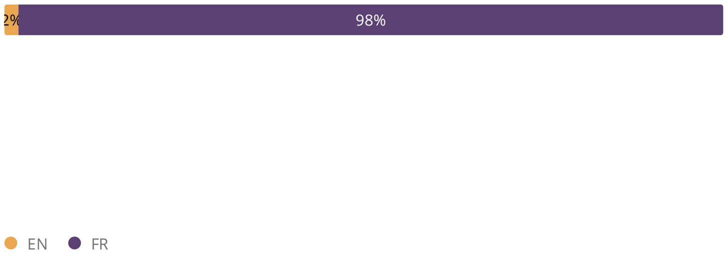
Appendix 1: Graphical Results - France

About the respondents

Response count

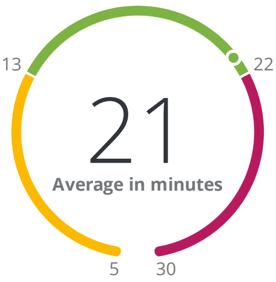


Responses per language 234 Responses

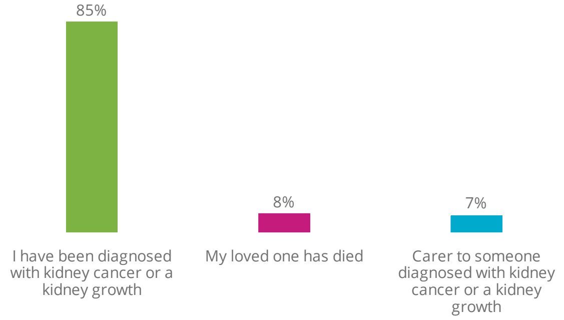


Average of minutes per response

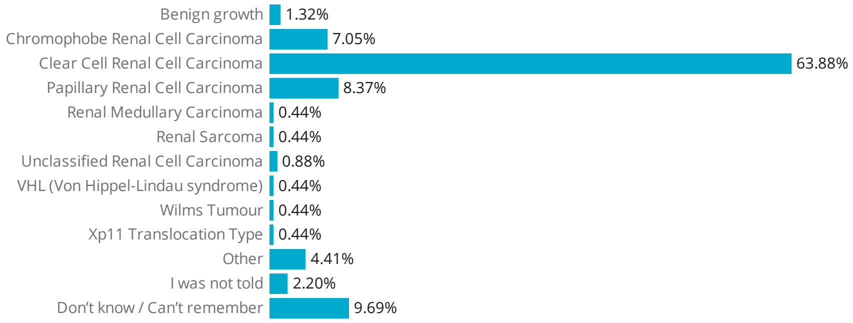
233 Responses



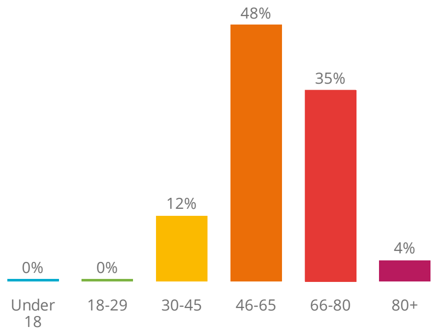
Described experience with kidney cancer 234 Responses



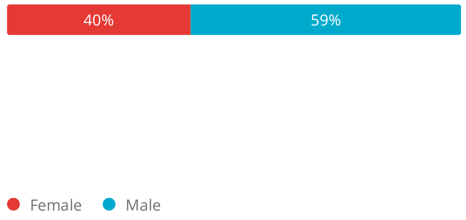
Sub-type of kidney cancer 227 Responses



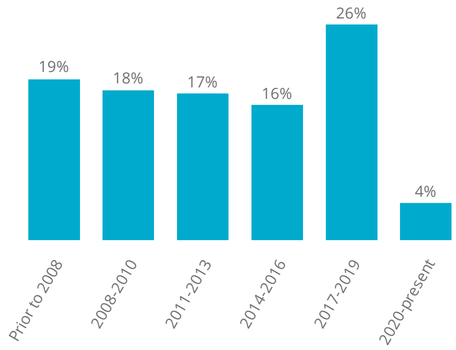
Age 231 Responses



Gender 234 Responses



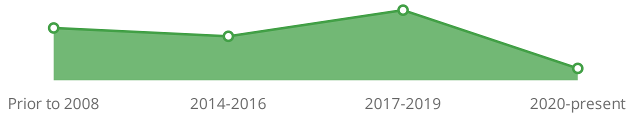
Diagnosis Year 231 Responses



Appendix 1: Graphical Results - France

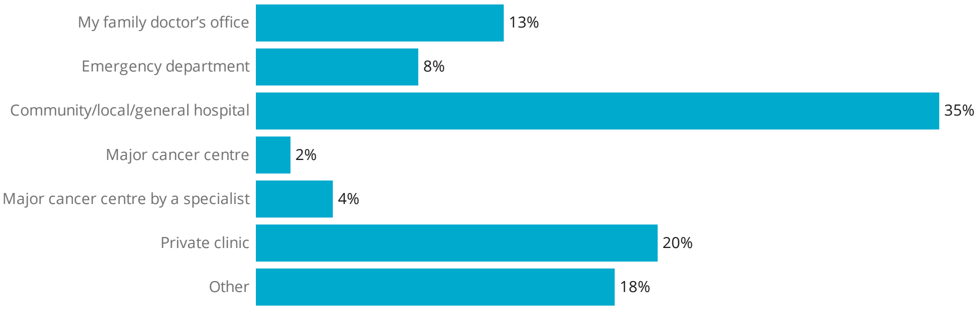
Diagnosis

Diagnosis Year **231** Responses

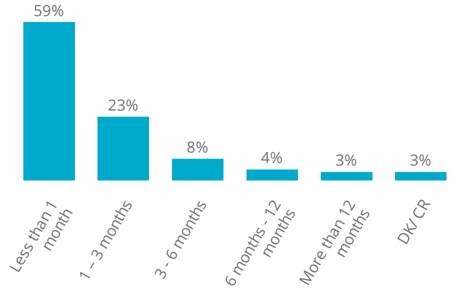


When first diagnosed were you told what subtype? **230** Responses

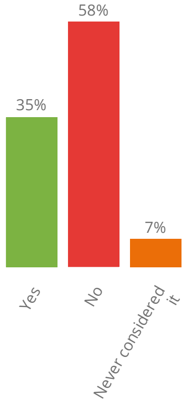
First correctly diagnosed **230** Responses



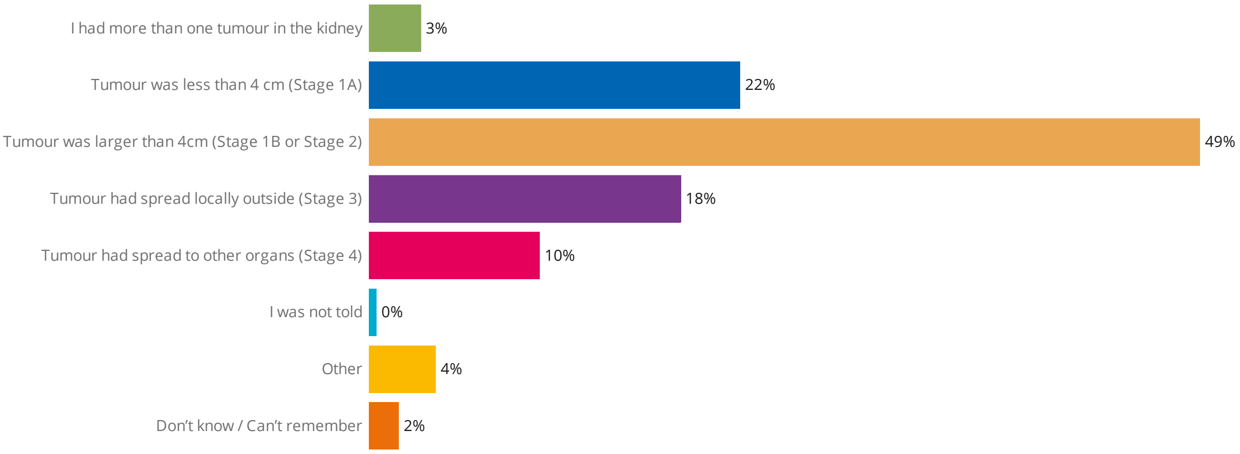
How long was it from the time you first thought something might be wrong with you to being CORRECTLY diagnosed? **230** Responses



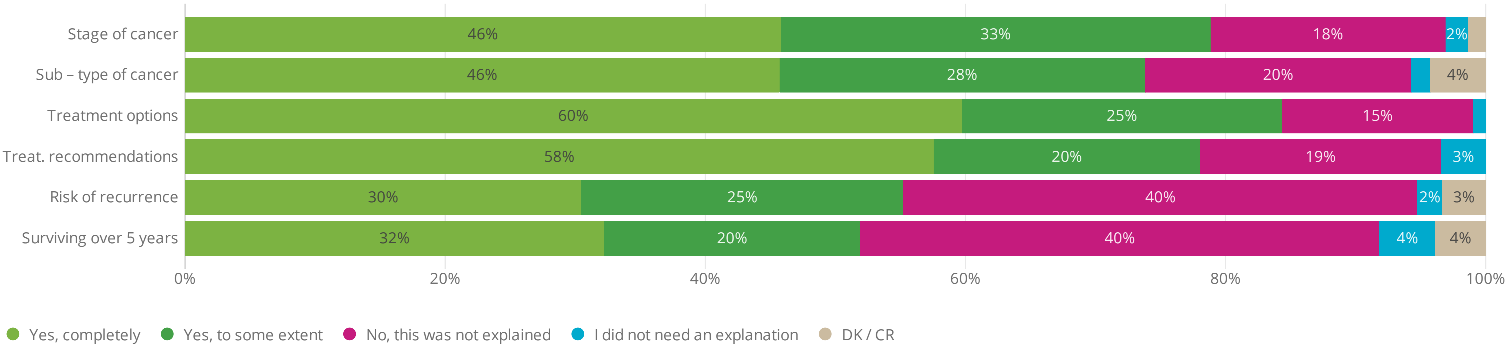
Did you ever seek a second opinion with a kidney cancer expert? **226** Responses



What stage when first diagnosed? **229** Responses



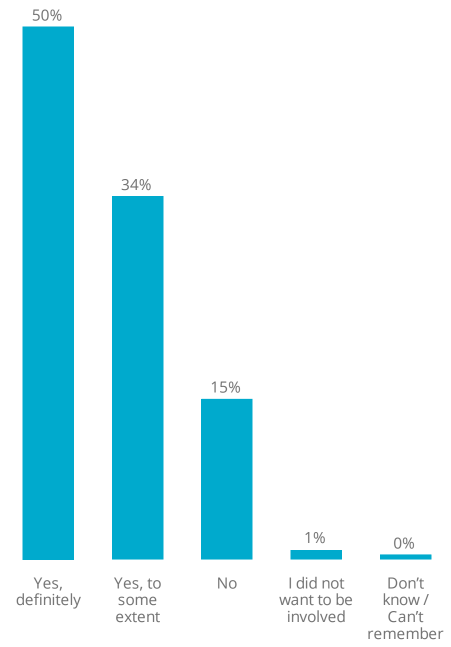
AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? **231** Responses



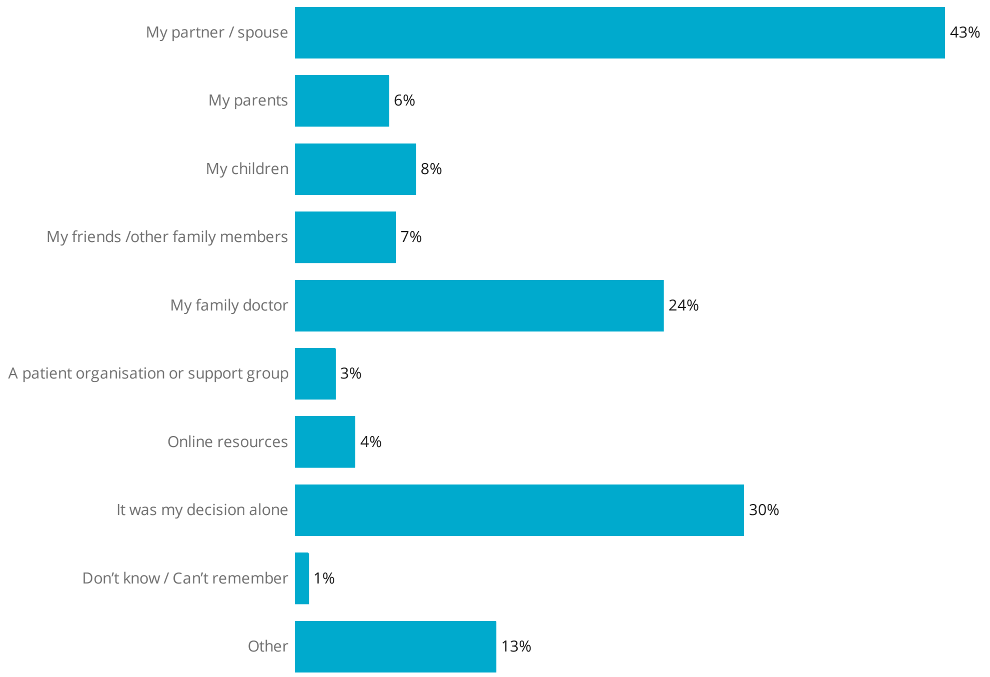
Appendix 1: Graphical Results - France

Developing a treatment plan

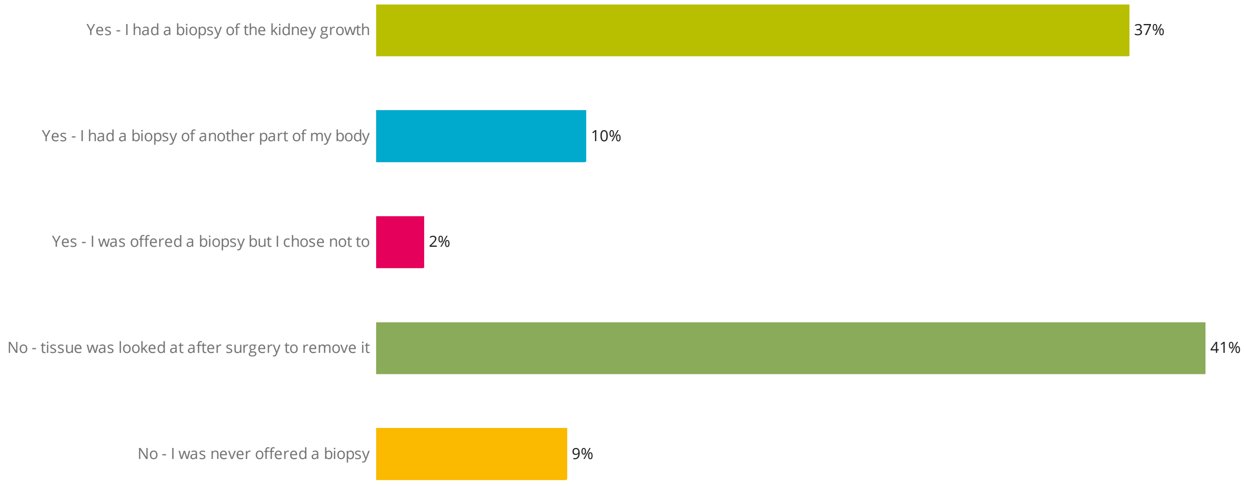
Were you involved as much as you wanted to be in decisions about your treatment plan? 227 Responses



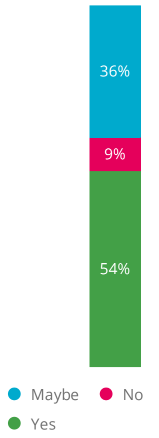
Who or what else helped you make decisions about your treatment plan? 227 Responses



Have you ever been offered a biopsy of some part of your body where kidney cancer was thought to be? 213 Responses



Would you be willing to have a biopsy in the future if necessary? 118 Responses

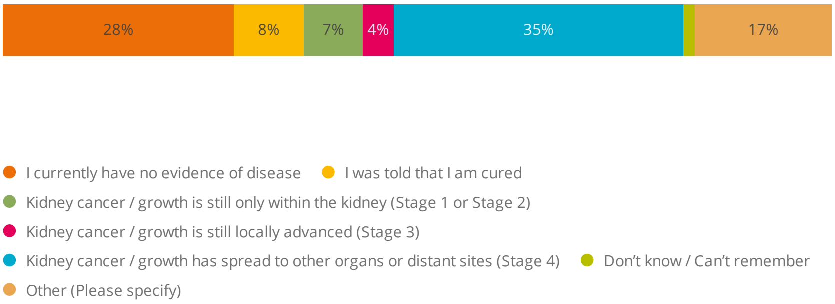


Appendix 1: Graphical Results - France

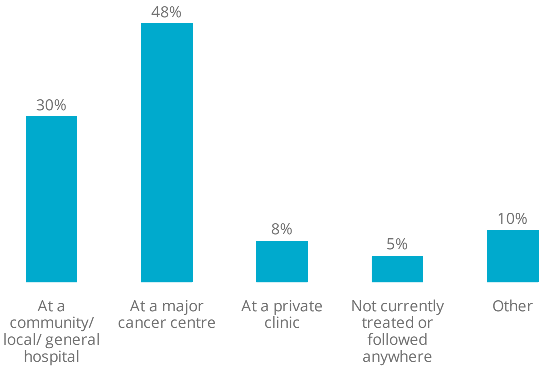
Your care and treatment & your care today

Which barriers (if any) have you experienced in receiving treatment for your kidney cancer or kidney growth? 223 Responses

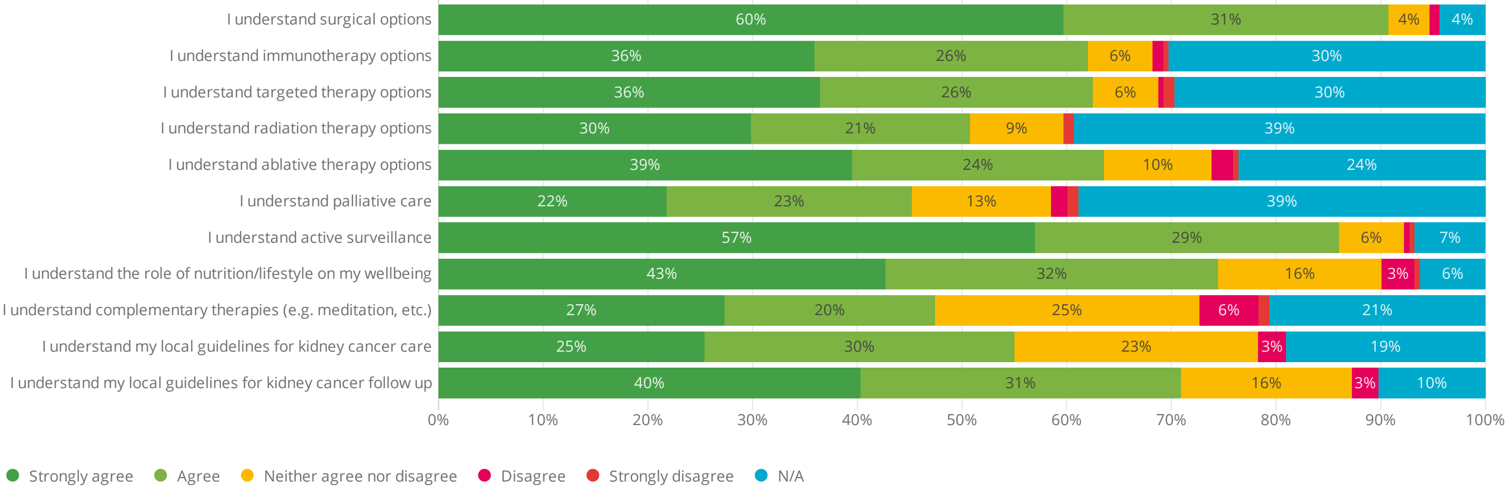
Which of the following best describes your stage of kidney cancer or kidney growth TODAY? 212 Responses



Where are you CURRENTLY being treated or followed? 210 Responses



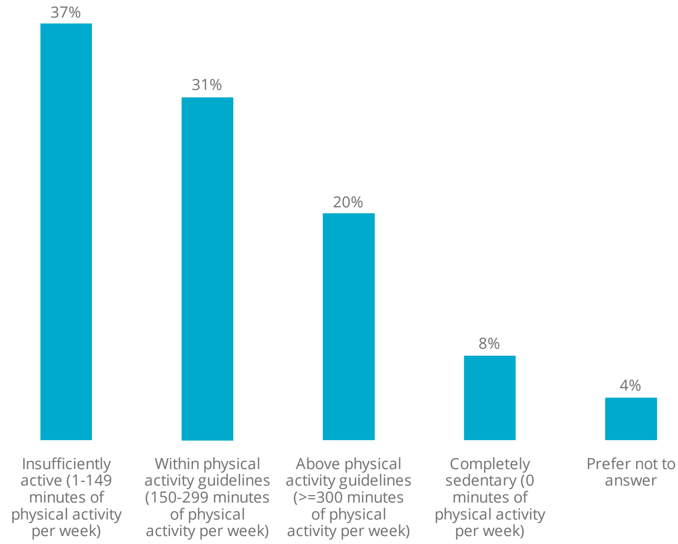
To what extent do you agree or disagree with the following statements?



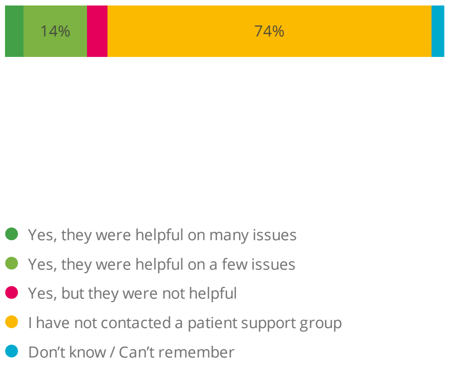
Appendix 1: Graphical Results - France

Quality of life

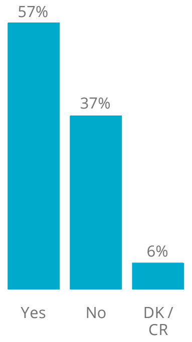
Current level of leisure-time physical activity 211 Responses



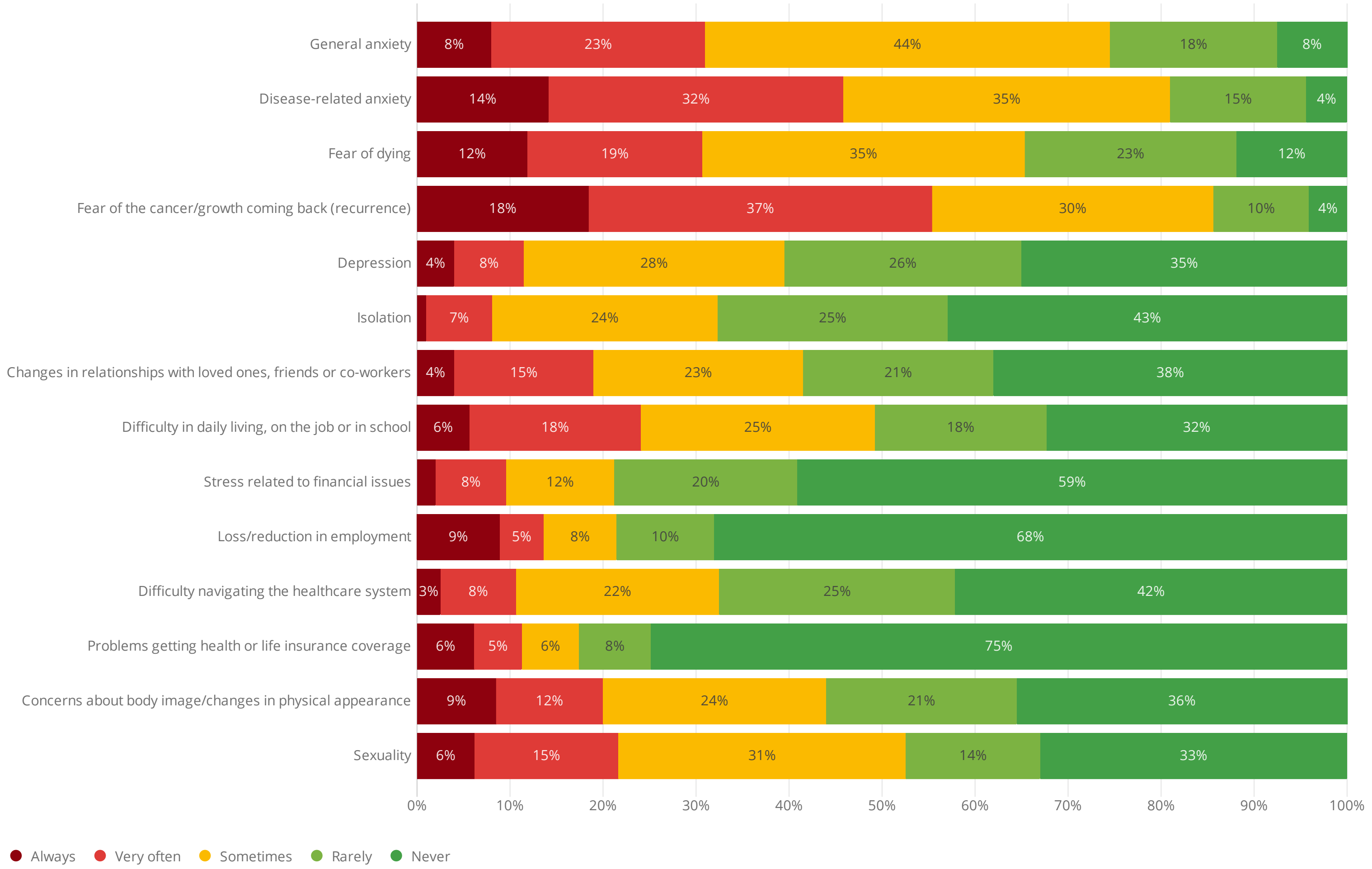
Have you ever used a patient support group (either in person or online) to help you with your kidney cancer / growth? 214 Responses



Have you ever talked to your doctor or to any other healthcare professional about any of these concerns? 196 Responses

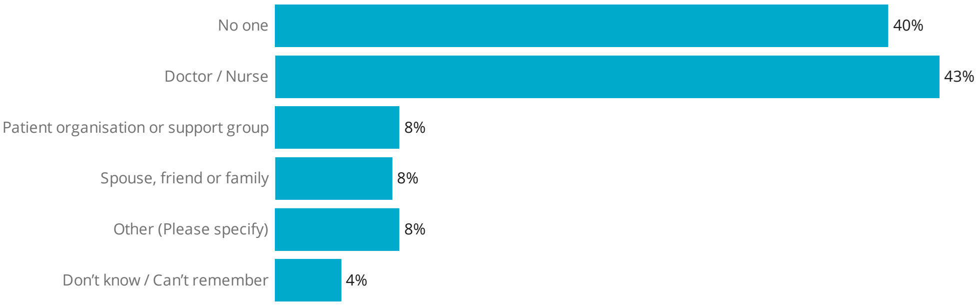


How often have the following impacted your sense of emotional well-being since your diagnosis?

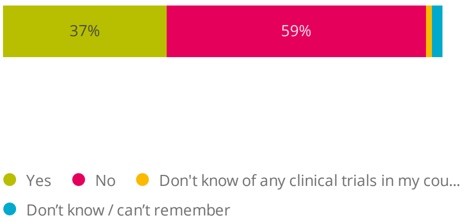


Cancer clinical trials

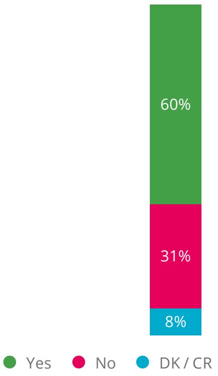
Who, if anyone, has discussed cancer clinical trials with you? 212 Responses



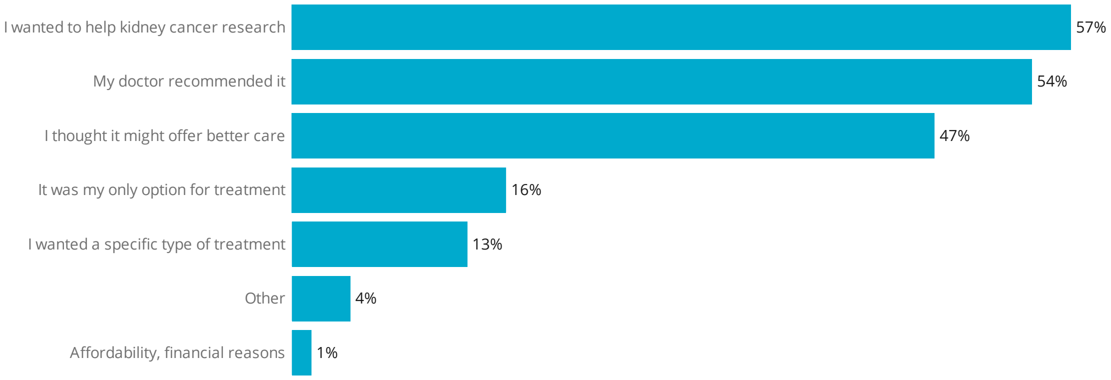
Have you ever been invited to participate in a cancer clinical trial? 215 Responses



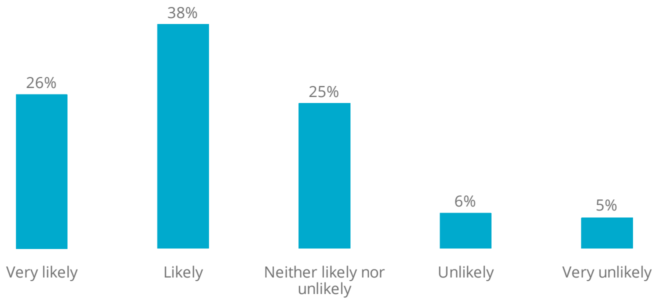
Did you agree to participate in the cancer clinical trial? 121 Responses



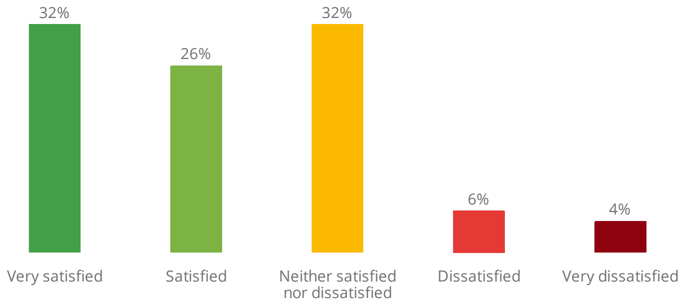
Why did you agree to participate? 70 Responses



If you had been or were invited, how likely is it that you would participate in a cancer clinical trial? 134 Responses



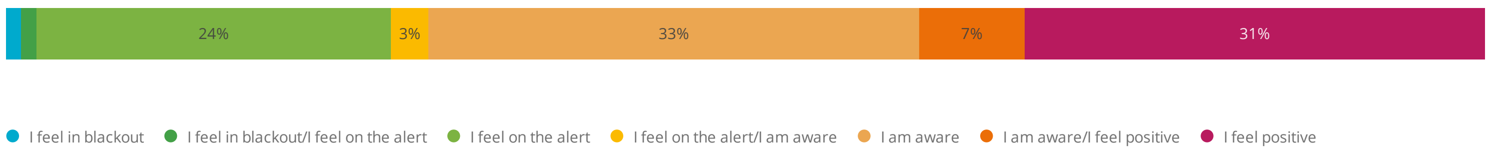
How satisfied were you overall with your cancer clinical trial experience? 69 Responses



Appendix 1: Graphical Results - France

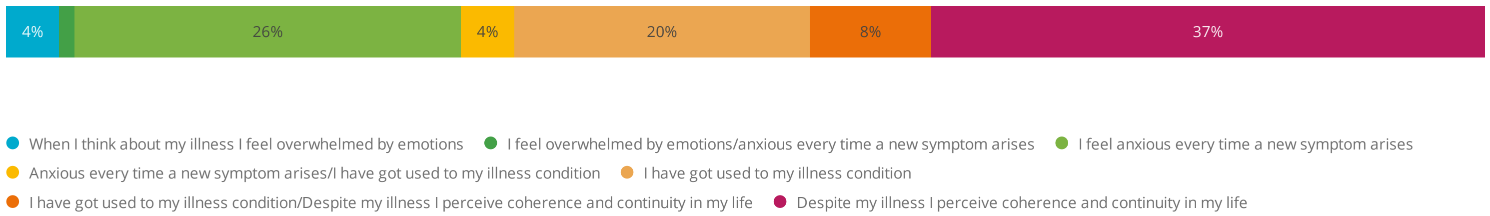
Patient Health Engagement scale from the Università Cattolica del Sacro Cuore

Thinking about my health status... 196 Responses

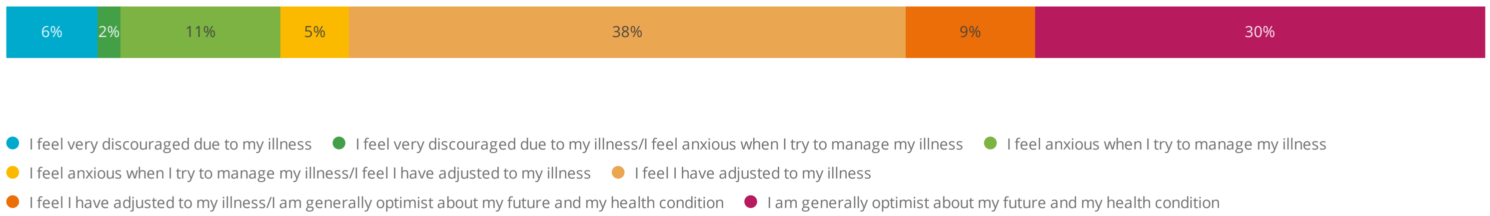


Thinking about my health status... 189 Responses

Thinking about my health status... 195 Responses



Thinking about my health status... 194 Responses



Thinking about my health status... 193 Responses

Appendix 2: Frequency Tables - France

About the respondents

About respondent 234 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	200	85%
My loved one has died	18	8%
I am a carer or caregiver to someone who has been diagnosed with kidney cancer or a kidney growth	16	7%
Total	234	100%

Sub-type of kidney cancer 227 Responses

Q2 - What sub-type of kidney cancer do you have?	Count ▲	Percent
Clear Cell Renal Cell Carcinoma	145	64%
Don't know / Can't remember	22	10%
Papillary Renal Cell Carcinoma	19	8%
Chromophobe Renal Cell Carcinoma	16	7%
Other	10	4%
I was not told	5	2%
Benign growth	3	1%
Unclassified Renal Cell Carcinoma	2	1%
Xp11 Translocation Type	1	0%
Wilms Tumour	1	0%
VHL (Von Hippel-Lindau syndrome)	1	0%
Renal Sarcoma (NOT Renal Cell Carcinoma with Sarcomatoid Appearance)	1	0%
Renal Medullary Carcinoma	1	0%
Total	227	100%

Age 231 Responses

Q4 - What is your age now?	Count ▲	Percent
46-65	110	48%
66-80	82	35%
30-45	28	12%
80+	9	4%
Under 18	1	0%
18-29	1	0%
Total	231	100%

Gender 234 Responses

Q5 - What is your gender?	Count ▲	Percent
Male	138	59%
Female	94	40%
I prefer to self describe	1	0%
Do not wish to identify	1	0%
Total	234	100%

Country of residence 234 Responses

Q3 - In which country do you currently reside?	Count	Percent
France	234	100%
Total	234	100%

Appendix 2: Frequency Tables - France

Diagnosis

Diagnosis Year 231 Responses

Q6 - In what year were you diagnosed?	Count ▲	Percent
2017-2019	59	26%
Prior to 2008	44	19%
2008-2010	41	18%
2011-2013	40	17%
2014-2016	37	16%
2020-present	10	4%
Total	231	100%

First correctly diagnosed 230 Responses

Q7 - Where was your kidney growth FIRST CORRECTLY DIAGNOSED?	Count ▲	Percent
Community/local/general hospital	80	35%
Private clinic	47	20%
Other	42	18%
My family doctor’s office	29	13%
Emergency department	19	8%
Major cancer centre by a specialist	9	4%
Major cancer centre	4	2%
Total	230	100%

When first diagnosed were you told what subtype? 230 Responses

Q8 - WHEN YOU WERE FIRST CORRECTLY DIAGNOSED, were you told what sub-type of kidney cancer or kidney growth you had?	Count ▲	Percent
Yes	116	50%
No	102	44%
Not sure	12	5%
Total	230	100%

When first diagnosed were you told what subtype? - Positive Score 218 Responses

Q8+ - WHEN YOU WERE FIRST CORRECTLY DIAGNOSED, were you told what sub-type of kidney cancer or kidney growth you had?	Count ▲	Percent
Yes	116	53%
No	102	47%
Total	218	100%

What stage when first diagnosed? 229 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)	112	49%
Tumour was less than 4 cm (Stage 1A)	50	22%
Tumour had spread locally outside (Stage 3)	42	18%
Tumour had spread to other organs (Stage 4)	23	10%
Other	9	4%
I had more than one tumour in the kidney	7	3%
Don’t know / Can’t remember	4	2%
I was not told	1	0%
Total	248	108%

Appendix 2: Frequency Tables - France

Diagnosis

How long to correct diagnosis? 230 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	135	59%
1 – 3 months	54	23%
3 - 6 months	18	8%
6 months - 12 months	9	4%
More than 12 months	7	3%
DK/ CR	7	3%
Total	230	100%

How long to correct diagnosis? - Positive Score 223 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	135	61%
1 – 3 months	54	24%
3 - 6 months	18	8%
6 months - 12 months	9	4%
More than 12 months	7	3%
Total	223	100%

Explanation at diagnosis - Stage of cancer 227 Responses

Q11a - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Stage of cancer	Count ▲	Percent
Yes, completely	104	46%
Yes, to some extent	75	33%
No, this was not explained	41	18%
I did not need an explanation	4	2%
Don't know / can't remember	3	1%
Total	227	100%

Explanation at diagnosis - Stage of cancer - Positive Score 220 Responses

Q11a+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Stage of cancer	Count ▲	Percent
Yes, completely	104	47%
Yes, to some extent	75	34%
No, this was not explained	41	19%
Total	220	100%

Explanation at diagnosis - Subtype of cancer 210 Responses

Q11b - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Subtype of cancer	Count ▲	Percent
Yes, completely	96	46%
Yes, to some extent	59	28%
No, this was not explained	43	20%
Don't know / can't remember	9	4%
I did not need an explanation	3	1%
Total	210	100%

Explanation at diagnosis - Subtype of cancer - Positive Score 198 Responses

Q11b+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Subtype of cancer	Count ▲	Percent
Yes, completely	96	48%
Yes, to some extent	59	30%
No, this was not explained	43	22%
Total	198	100%

Diagnosis

Explanation at diagnosis - Treatment options 211 Responses

Q11c - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment options	Count ▲	Percent
Yes, completely	126	60%
Yes, to some extent	52	25%
No, this was not explained	31	15%
I did not need an explanation	2	1%
Total	211	100%

Explanation at diagnosis - Treatment options - Positive Score 209 Responses

Q11c+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment options	Count ▲	Percent
Yes, completely	126	60%
Yes, to some extent	52	25%
No, this was not explained	31	15%
Total	209	100%

Explanation at diagnosis - Treatment recommendations 205 Responses

Q11d - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment recommendations	Count ▲	Percent
Yes, completely	118	58%
Yes, to some extent	42	20%
No, this was not explained	38	19%
I did not need an explanation	7	3%
Total	205	100%

Explanation at diagnosis - Treatment recommendations - Positive Score 198 Responses

Q11d+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment recommendations	Count ▲	Percent
Yes, completely	118	60%
Yes, to some extent	42	21%
No, this was not explained	38	19%
Total	198	100%

Explanation at diagnosis - Risk of recurrence 210 Responses

Q11e - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Risk of recurrence	Count ▲	Percent
No, this was not explained	83	40%
Yes, completely	64	30%
Yes, to some extent	52	25%
Don’t know / can’t remember	7	3%
I did not need an explanation	4	2%
Total	210	100%

Explanation at diagnosis - Risk of recurrence - Positive Score 199 Responses

Q11e+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Risk of recurrence	Count ▲	Percent
No, this was not explained	83	42%
Yes, completely	64	32%
Yes, to some extent	52	26%
Total	199	100%

Diagnosis

Explanation at diagnosis - Likelihood of surviving beyond 5 yrs 208 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	83	40%
Yes, completely	67	32%
Yes, to some extent	41	20%
I did not need an explanation	9	4%
Don’t know / can’t remember	8	4%
Total	208	100%

Explanation at diagnosis - Likelihood of surviving beyond 5 yrs - Positive Score 191 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	83	43%
Yes, completely	67	35%
Yes, to some extent	41	21%
Total	191	100%

Second opinion 226 Responses

Q12 - Did you ever seek a second opinion with a kidney cancer expert?	Count ▲	Percent
No	131	58%
Yes	80	35%
Never considered it	15	7%
Total	226	100%

Appendix 2: Frequency Tables - France

Developing a treatment plan

Involvement in treatment plan 227 Responses

Q13 - Were you involved as much as you wanted to be in decisions about your treatment plan?	Count ▲	Percent
Yes, definitely	113	50%
Yes, to some extent	77	34%
No	34	15%
I did not want to be involved	2	1%
Don't know / Can't remember	1	0%
Total	227	100%

Involvement in treatment plan - Positive Score 224 Responses

Q13+ - Were you involved as much as you wanted to be in decisions about your treatment plan?	Count ▲	Percent
Yes, definitely	113	50%
Yes, to some extent	77	34%
No	34	15%
Total	224	100%

Support in treatment plan decisions 227 Responses

Q14 - Who or what else helped you make decisions about your treatment plan? (PLEASE CHOOSE ALL THAT APPLY)	Count ▲	Percent
My partner / spouse	97	43%
It was my decision alone	67	30%
My family doctor	55	24%
Other	30	13%
My children	18	8%
My friends /other family members	15	7%
My parents	14	6%
Online resources	9	4%
A patient organisation or support group	6	3%
Don't know / Can't remember	2	1%
Total	313	138%

Barriers to treatment 223 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	169	76%
Other barrier not mentioned above	18	8%
No speciality doctor locally	10	4%
Wait time to treatment was an issue for me	9	4%
No access to up-to-date treat. or equipment	9	4%
Lack of personal support	8	4%
No access to treatment centre / travel	5	2%
Difficulty managing carer role while in treat.	5	2%
Cost of treatment	3	1%
No available treatments	2	1%
Fear of discrimination if knew about disease	2	1%
Total	240	108%

Appendix 2: Frequency Tables - France

Your care and treatment & your care today

Stage of kidney cancer or kidney growth TODAY 212 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)	74	35%
I currently have no evidence of disease	59	28%
Other (Please specify)	35	17%
I was told that I am cured	18	8%
Kidney cancer / growth is still only within the kidney (Stage 1 or Stage 2)	15	7%
Kidney cancer / growth is still locally advanced (Stage 3)	8	4%
Don't know / Can't remember	3	1%
Total	212	100%

Treatment TODAY 210 Responses

Q17 - Where are you CURRENTLY being treated or followed?	Count	Percent
At a major cancer centre	100	48%
At a community/ local/ general hospital	64	30%
Other	20	10%
At a private clinic	16	8%
Not currently treated or followed anywhere	10	5%
Total	210	100%

Understanding of care/treatment - Surgical options 206 Responses

Q18a - I understand surgical options	Count	Percent
Strongly agree	123	60%
Agree	64	31%
N/A	9	4%
Neither agree nor disagree	8	4%
Disagree	2	1%
Total	206	100%

Understanding of care/treatment - Surgical options - Positive Score 197 Responses

Q18a+ - I understand surgical options	Count	Percent
Strongly agree	123	62%
Agree	64	32%
Neither agree nor disagree	8	4%
Disagree	2	1%
Total	197	100%

Understanding of care/treatment - Immunotherapy options 195 Responses

Q18b - I understand immunotherapy options	Count	Percent
Strongly agree	70	36%
N/A	59	30%
Agree	51	26%
Neither agree nor disagree	12	6%
Disagree	2	1%
Strongly disagree	1	1%
Total	195	100%

Understanding of care/treatment - Immunotherapy options - Positive Score 136 Responses

Q18b+ - I understand immunotherapy options	Count	Percent
Strongly agree	70	51%
Agree	51	38%
Neither agree nor disagree	12	9%
Disagree	2	1%
Strongly disagree	1	1%
Total	136	100%

Appendix 2: Frequency Tables - France

Your care and treatment & your care today

Understanding of care/treatment - Targeted therapy options 192 Responses

Q18c - I understand targeted therapy options	Count ▲	Percent
Strongly agree	70	36%
N/A	57	30%
Agree	50	26%
Neither agree nor disagree	12	6%
Strongly disagree	2	1%
Disagree	1	1%
Total	192	100%

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

Q18c+ -I understand targeted therapy options	Count ▲	Percent
Strongly agree	70	52%
Agree	50	37%
Neither agree nor disagree	12	9%
Strongly disagree	2	1%
Disagree	1	1%
Total	135	100%

Understanding of care/treatment - Radiation therapy options 191 Responses

Q18d - I understand radiation therapy options	Count ▲	Percent
N/A	75	39%
Strongly agree	57	30%
Agree	40	21%
Neither agree nor disagree	17	9%
Strongly disagree	2	1%
Total	191	100%

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

Q18d+ - I understand radiation therapy options	Count ▲	Percent
Strongly agree	57	49%
Agree	40	34%
Neither agree nor disagree	17	15%
Strongly disagree	2	2%
Total	116	100%

Understanding of care/treatment - Ablative therapy options 195 Responses

Q18e - I understand ablative therapy options	Count ▲	Percent
Strongly agree	77	39%
Agree	47	24%
N/A	46	24%
Neither agree nor disagree	20	10%
Disagree	4	2%
Strongly disagree	1	1%
Total	195	100%

Understanding of care/treatment - Ablative therapy options - Positive Score 149 Responses

Q18e+ - I understand ablative therapy options	Count ▲	Percent
Strongly agree	77	52%
Agree	47	32%
Neither agree nor disagree	20	13%
Disagree	4	3%
Strongly disagree	1	1%
Total	149	100%

Appendix 2: Frequency Tables - France

Your care and treatment & your care today

Understanding of care/treatment - Palliative 188 Responses

Q18f - I understand palliative care	Count ▲	Percent
N/A	73	39%
Agree	44	23%
Strongly agree	41	22%
Neither agree nor disagree	25	13%
Disagree	3	2%
Strongly disagree	2	1%
Total	188	100%

Understanding of care/treatment - Palliative - Positive Score 115 Responses

Q18f+ - I understand palliative care	Count ▲	Percent
Agree	44	38%
Strongly agree	41	36%
Neither agree nor disagree	25	22%
Disagree	3	3%
Strongly disagree	2	2%
Total	115	100%

Understanding of care/treatment - Active Surveillance 193 Responses

Q18g -I understand active surveillance	Count ▲	Percent
Strongly agree	110	57%
Agree	56	29%
N/A	13	7%
Neither agree nor disagree	12	6%
Strongly disagree	1	1%
Disagree	1	1%
Total	193	100%

Understanding of care/treatment - Active Surveillance - Positive Score 180 Responses

Q18g+ -I understand active surveillance	Count ▲	Percent
Strongly agree	110	61%
Agree	56	31%
Neither agree nor disagree	12	7%
Strongly disagree	1	1%
Disagree	1	1%
Total	180	100%

Understanding of care/treatment - Role of nutrition/lifestyle 192 Responses

Q18h - I understand the role of nutrition/lifestyle on my wellbeing	Count ▲	Percent
Strongly agree	82	43%
Agree	61	32%
Neither agree nor disagree	30	16%
N/A	12	6%
Disagree	6	3%
Strongly disagree	1	1%
Total	192	100%

Understanding of care/treatment - Role of nutrition/lifestyle - Positive Score 180 Responses

Q18h+ - I understand the role of nutrition/lifestyle on my wellbeing	Count ▲	Percent
Strongly agree	82	46%
Agree	61	34%
Neither agree nor disagree	30	17%
Disagree	6	3%
Strongly disagree	1	1%
Total	180	100%

Your care and treatment & your care today

Understanding of care/treatment - Complementary therapies 194 Responses

Q18i - I understand complementary therapies (e.g. meditation, etc.)	Count ▲	Percent
Strongly agree	53	27%
Neither agree nor disagree	49	25%
N/A	40	21%
Agree	39	20%
Disagree	11	6%
Strongly disagree	2	1%
Total	194	100%

Understanding of care/treatment - Complementary therapies - Positive Score 154 Responses

Q18i+ - I understand complementary therapies (e.g. meditation, etc.)	Count ▲	Percent
Strongly agree	53	34%
Neither agree nor disagree	49	32%
Agree	39	25%
Disagree	11	7%
Strongly disagree	2	1%
Total	154	100%

Understanding of care/treatment - Local guidelines for care 189 Responses

Q18j - I understand my local guidelines for kidney cancer care	Count ▲	Percent
Agree	56	30%
Strongly agree	48	25%
Neither agree nor disagree	44	23%
N/A	36	19%
Disagree	5	3%
Total	189	100%

Understanding of care/treatment - Local guidelines for care - Positive Score 153 Responses

Q18j+ - I understand my local guidelines for kidney cancer care	Count ▲	Percent
Agree	56	37%
Strongly agree	48	31%
Neither agree nor disagree	44	29%
Disagree	5	3%
Total	153	100%

Understanding of care/treatment - Local guidelines for follow up 196 Responses

Q18k - I understand my local guidelines for kidney cancer follow up	Count ▲	Percent
Strongly agree	79	40%
Agree	60	31%
Neither agree nor disagree	32	16%
N/A	20	10%
Disagree	5	3%
Total	196	100%

Understanding of care/treatment - Local guidelines for follow up - Positive Score 176 Responses

Q18k+ - I understand my local guidelines for kidney cancer follow up	Count ▲	Percent
Strongly agree	79	45%
Agree	60	34%
Neither agree nor disagree	32	18%
Disagree	5	3%
Total	176	100%

Your care and treatment & your care today

Biopsy experience 213 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	87	41%
Yes - I had a biopsy of the kidney growth	79	37%
Yes - I had a biopsy of another part of my body	22	10%
No - I was never offered a biopsy	20	9%
Yes - I was offered a biopsy but I chose not to	5	2%
Total	213	100%

Biopsy 118 Responses

Q20 - Would you be willing to have a biopsy in the future if necessary?	Count ▲	Percent
Yes	64	54%
Maybe	43	36%
No	11	9%
Total	118	100%

Quality of life

Physical activity 211 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)	79	37%
Within physical activity guidelines (150-299 minutes of physical activity per week)	65	31%
Above physical activity guidelines (>=300 minutes of physical activity per week)	43	20%
Completely sedentary (0 minutes of physical activity per week)	16	8%
Prefer not to answer.	8	4%
Total	211	100%

Physical activity - Positive Score 203 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)	79	39%
Within physical activity guidelines (150-299 minutes of physical activity per week)	65	32%
Above physical activity guidelines (≥300 minutes of physical activity per week)	43	21%
Completely sedentary (0 minutes of physical activity per week)	16	8%
Total	203	100%

Emotional well-being - General anxiety 200 Responses

Q22a - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Sometimes	87	44%
Very often	46	23%
Rarely	36	18%
Always	16	8%
Never	15	8%
Total	200	100%

Emotional well-being - Disease related anxiety 205 Responses

Q22b - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Sometimes	72	35%
Very often	65	32%
Rarely	30	15%
Always	29	14%
Never	9	4%
Total	205	100%

Emotional well-being - Fear of dying 202 Responses

Q22c - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Sometimes	70	35%
Rarely	46	23%
Very often	38	19%
Never	24	12%
Always	24	12%
Total	202	100%

Emotional well-being - Fear of cancer/growth coming back 195 Responses

Q22d - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Very often	72	37%
Sometimes	59	30%
Always	36	18%
Rarely	20	10%
Never	8	4%
Total	195	100%

Quality of life

Emotional well-being - Depression 200 Responses

Q22e - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	70	35%
Sometimes	56	28%
Rarely	51	26%
Very often	15	8%
Always	8	4%
Total	200	100%

Emotional well-being - Isolation 198 Responses

Q22f - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	85	43%
Rarely	49	25%
Sometimes	48	24%
Very often	14	7%
Always	2	1%
Total	198	100%

Emotional well-being - Changes in relationships 200 Responses

Q22g - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	76	38%
Sometimes	45	23%
Rarely	41	21%
Very often	30	15%
Always	8	4%
Total	200	100%

Emotional well-being - Difficulty in daily living 195 Responses

Q22h - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	63	32%
Sometimes	49	25%
Very often	36	18%
Rarely	36	18%
Always	11	6%
Total	195	100%

Emotional well-being - Stress related to financial issues 198 Responses

Q22i - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	117	59%
Rarely	39	20%
Sometimes	23	12%
Very often	15	8%
Always	4	2%
Total	198	100%

Emotional well-being - Loss/reduction in employment 191 Responses

Q22j - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	130	68%
Rarely	20	10%
Always	17	9%
Sometimes	15	8%
Very often	9	5%
Total	191	100%

Quality of life

Emotional well-being - Difficulty navigating the healthcare system

197 Responses

Q22k - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	83	42%
Rarely	50	25%
Sometimes	43	22%
Very often	16	8%
Always	5	3%
Total	197	100%

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

195 Responses

Q22l - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	146	75%
Rarely	15	8%
Sometimes	12	6%
Always	12	6%
Very often	10	5%
Total	195	100%

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

200 Responses

Q22m - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	71	36%
Sometimes	48	24%
Rarely	41	21%
Very often	23	12%
Always	17	9%

Emotional well-being - Sexuality

194 Responses

Q22n - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	64	33%
Sometimes	60	31%
Very often	30	15%
Rarely	28	14%
Always	12	6%
Total	194	100%

Quality of life

Seeking support from medical professional 196 Responses

Q24 - Have you ever talked to your doctor or to any other healthcare professional about any of these concerns?	Count ▲	Percent
Yes	112	57%
No	73	37%
Don't know / Can't remember	11	6%
Total	196	100%

Seeking support from medical professional - Positive Score 185 Responses

Q24+ - Have you ever talked to your doctor or to any other healthcare professional about any of these concerns?	Count ▲	Percent
Yes	112	61%
No	73	39%
Total	185	100%

Seeking support from PSG 214 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	158	74%
Yes, they were helpful on a few issues	31	14%
Yes, but they were not helpful	10	5%
Yes, they were helpful on many issues	9	4%
Don't know / Can't remember	6	3%
Total	214	100%

Seeking support from PSG - Positive Score 208 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	158	76%
Yes, they were helpful on a few issues	31	15%
Yes, but they were not helpful	10	5%
Yes, they were helpful on many issues	9	4%
Total	208	100%

Cancer clinical trials

Discussion with whom 212 Responses

Q26 - Who, if anyone, has discussed cancer clinical trials with you? (PLEASE CHOOSE ALL THAT APPLY)	Count ▲	Percent
Doctor / Nurse	91	43%
No one	84	40%
Patient organisation or support group	17	8%
Other (Please specify)	17	8%
Spouse, friend or family	16	8%
Don't know / Can't remember	9	4%
Total	234	110%

Invitation to cancer clinical trials 215 Responses

Q27 - Have you ever been invited to participate in a cancer clinical trial?	Count ▲	Percent
No	127	59%
Yes	80	37%
Don't know / can't remember	5	2%
Don't know of any clinical trials in my country	3	1%
Total	215	100%

Invitation to cancer clinical trials - Positive Score 210 Responses

Q27+ - Have you ever been invited to participate in a cancer clinical trial?	Count ▲	Percent
No	127	60%
Yes	80	38%
I do not know of any clinical trials in my country	3	1%

Actually participated 121 Responses

Q28 - Did you agree to participate in the cancer clinical trial?	Count ▲	Percent
Yes	73	60%
No	38	31%
DK / CR	10	8%
Total	121	100%

Actually participated - Positive Score 111 Responses

Q28+ - Did you agree to participate in the cancer clinical trial?	Count ▲	Percent
Yes	73	66%
No	38	34%
Total	111	100%

Cancer clinical trials

Reasons for participation 70 Responses

Q29 - Why did you agree to participate? (PLEASE CHOOSE ALL THAT APPLY)	Count ▲	Percent
I wanted to help kidney cancer research	40	57%
My doctor recommended it	38	54%
I thought it might offer better care	33	47%
It was my only option for treatment	11	16%
I wanted a specific type of treatment	9	13%
Other	3	4%
Affordability, financial reasons	1	1%
Total	135	193%

Satisfaction with overall experience of clinical trial 69 Responses

Q30 - How satisfied were you overall with your cancer clinical trial experience?	Count ▲	Percent
Very satisfied	22	32%
Neither satisfied nor dissatisfied	22	32%
Satisfied	18	26%
Dissatisfied	4	6%
Very dissatisfied	3	4%
Total	69	100%

Potential participation 134 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	51	38%
Very likely	35	26%
Neither likely nor unlikely	33	25%
Unlikely	8	6%
Very unlikely	7	5%
Total	134	100%

Appendix 2: Frequency Tables - France

Patient Health Engagement scale from the Università Cattolica del Sacro Cuore

Thinking about my health status... 196 Responses

Q32 - I feel in blackout - I feel on alert - I am aware - I feel positive	Count ▲	Percent
I am aware	65	33%
I feel positive	61	31%
I feel on the alert	47	24%
I am aware/I feel positive	14	7%
I feel on the alert/I am aware	5	3%
I feel in blackout/I feel on the alert	2	1%
I feel in blackout	2	1%
Total	196	100%

Thinking about my health status... 189 Responses

Q33 - I feel dazed - I am in alarm - I am conscious - I feel serene	Count ▲	Percent
I am conscious	115	61%
I feel serene	38	20%
I am conscious/I feel serene	12	6%
I am in alarm	11	6%
I feel dazed	6	3%
I am in alarm/I am conscious	6	3%
I feel dazed/I am in alarm	1	1%
Total	189	100%

Thinking about my health status... 195 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	73	37%
I feel anxious every time a new symptom arises	51	26%
I have got used to my illness condition	39	20%
I have got used to my illness condition/Despite my illness I perceive coherence and continuity in my life	16	8%
When I think about my illness I feel overwhelmed by emotions	7	4%
Anxious every time a new symptom arises/I have got used to my illness condition	7	4%
I feel overwhelmed by emotions/anxious every time a new symptom arises	2	1%
Total	195	100%

Thinking about my health status... 194 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	73	38%
I am generally optimist about my future and my health condition	59	30%
I feel anxious when I try to manage my illness	21	11%
I feel I have adjusted to my illness/I am generally optimist about my future and my health condition	17	9%
I feel very discouraged due to my illness	12	6%
I feel anxious when I try to manage my illness/I feel I have adjusted to my illness	9	5%
I feel very discouraged due to my illness/I feel anxious when I try to manage my illness	3	2%
Total	194	100%

Patient Health Engagement scale from the Università Cattolica del Sacro Cuore

Thinking about my health status... 193 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	77	40%
I feel I have accepted my illness	57	30%
I am upset when a new symptom arises	28	15%
I feel I have accepted my illness/I can give sense to my life despite my illness condition	19	10%
I am upset when a new symptom arises/I feel I have accepted my illness	7	4%
I feel totally oppressed by my illness	3	2%
I feel totally oppressed by my illness/I am upset when a new symptom arises	2	1%
Total	193	100%

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
www.picker.org

Charity registered in England and Wales: 1081688
Charity registered in Scotland: SC045048
Company limited by guarantee registered in England and Wales: 3908160