International Kidney Cancer Coalition Global Survey 2020

United Kingdom – England 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.

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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[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

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[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.

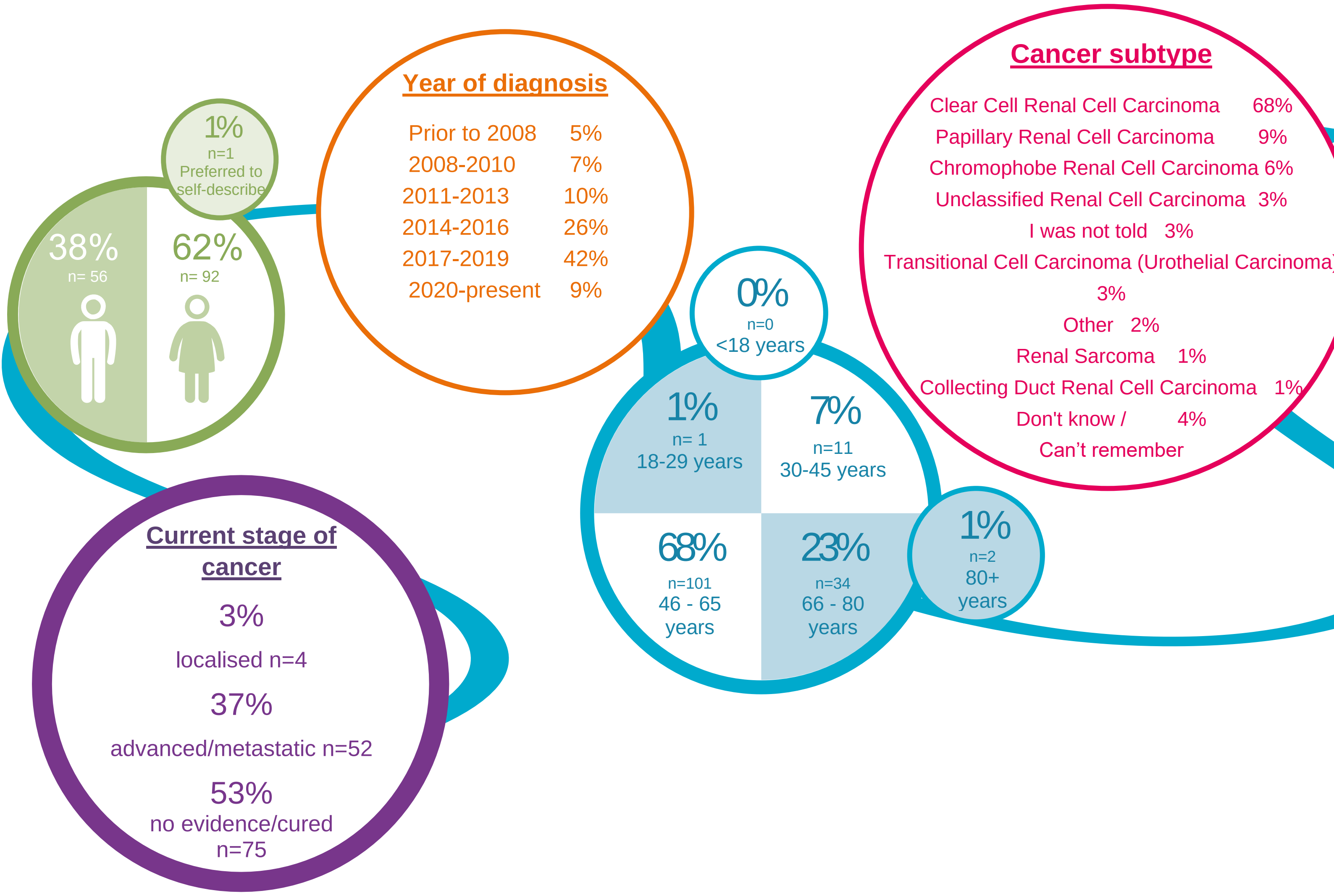
Survey activity

This report outlines the results from the **149** respondents from England. Comprised of:

138 patients

11 carers or caregivers

0 undisclosed



1%
n=1
Preferred to self-describe

38%
n= 56

62%
n= 92

Year of diagnosis

Prior to 2008	5%
2008-2010	7%
2011-2013	10%
2014-2016	26%
2017-2019	42%
2020-present	9%

0%
n=0
<18 years

1%
n= 1
18-29 years

7%
n=11
30-45 years

68%
n=101
46 - 65 years

23%
n=34
66 - 80 years

1%
n=2
80+ years

Cancer subtype

Clear Cell Renal Cell Carcinoma	68%
Papillary Renal Cell Carcinoma	9%
Chromophobe Renal Cell Carcinoma	6%
Unclassified Renal Cell Carcinoma	3%
I was not told	3%
Transitional Cell Carcinoma (Urothelial Carcinoma	3%
Other	2%
Renal Sarcoma	1%
Collecting Duct Renal Cell Carcinoma	1%
Don't know / Can't remember	4%

Current stage of cancer

3%
localised n=4

37%
advanced/metastatic n=52

53%
no evidence/cured n=75

Key results

Patient knowledge, expectations of treatment and shared decision making:

Time to diagnosis – see page 6

65% of respondents reported that it was less than 3 months between their first thinking that there might be something wrong to when they were correctly diagnosed

Shared decision making – see page 7

59% 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

91% felt that ‘treatment recommendations’ were completely/to some extent understood at diagnosis

53% reported that the likelihood of surviving their cancer beyond five years was not explained

Barriers to treatment – see page 8

43% of respondents reported experiencing barriers to treatment

Biopsy – see page 8

28% of respondents had a biopsy (20% of the kidney; 8% of other sites)

1% 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

62% of respondents indicated that “No one” discussed cancer clinical trials with them.

Experience of clinical trials – see page 10

27% of respondents were invited to take part in a clinical trial

78% of those who took part in a clinical trial were satisfied with their experience overall

3% were dissatisfied with their clinical trial experience

Quality of life and overall health status of respondents:

Level of physical activity – see page 10

51% 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

43% of respondents indicated that they ‘very often’ or ‘always’ experienced disease-related anxiety

40% of respondents indicated that they ‘very often’ or ‘always’ experienced general anxiety

Seeking support – see page 11

43% of respondents reported having talked to their doctor / healthcare professional about their concerns

Summary of results – England

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 – England.

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

9% (n=14) of respondents from England received a diagnosis in the year prior to taking to the survey (between 2020 and 2021). 42% (n=63) of respondents received a diagnosis between 2017 and 2019, whereas 48% (n=72) received a diagnosis in 2016 or prior[4].

Stage of kidney tumour(s) at diagnosis

19% (n=29) of respondents who were residents of England 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.

4% (n=6) of respondents from England 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 England, 33% (n=48) of respondents reported receiving a diagnosis in under 1 month.

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[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. 69% (n=95) of respondents in England indicated that this was the case.

At diagnosis (England respondents):

- 68% (n=98) completely or to some extent understood ‘stage of cancer’ (Globally this was 85%, n=1576)
- 89% (n=116) completely or to some extent understood ‘treatment options’ (Globally this was 88%, n=1603)
- 91% (n=118) felt that ‘treatment recommendations’ were completely/to some extent understood (Globally 88%, n=1569)
- 54% (n=67) said that cancer subtype was not explained (Globally 34%, n=587)
- 40% (n=53) said that risk of recurrence was not explained (Globally 31%, n=550)
- 53% (n=68) 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, 12% (n=18) of respondents in England reported ever having received a second opinion (globally 38%, n=733). 71% (n=105) reported that they decided not to get a second opinion (globally 51%, n=982). Whereas 5% (n=7) said that this was not an option to them (globally 4%, n=75) and 12% (n=17) 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 England, this accounted for 59% (n=85) 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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[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.

England, 68% (n=99) indicated that this was the case. In addition, 9% (n=13) indicated that their friends/other family members were involved.

16% (n=23) indicated that they consulted their children and 14% (n=21) used online resources.

Barriers to treatment

57% of respondents (n=78) reported experiencing no barriers to treatment, relative to 44% (n=839) globally. The most commonly experienced barriers reported from respondents in England were:

- Lack of personal support – 49% of respondents (n=29)
- Wait time to treatment – 41% of respondents (n=24)
- Other barrier – 19% of respondents (n=11)
- Lack of access to the most up-to-date treatment or equipment – 19% of respondents (n=11)
- No speciality doctor locally – 17% of respondents (n=10)
- Difficulty managing my carer/caregiver role (child, parent, disabled person) while in treatment – 17% of respondents (n=10)

Stage of kidney tumour(s) today

At the time of completing the survey, 53% (n=75) of respondents in England indicated that they had no evidence of disease / were cured. 3% (n=4) of respondents noted that their tumour was still only within the kidney (stage 1 or 2). Whereas 37% (n=52) of respondents indicated that their cancer was advanced/metastasised.

Biopsy practice

Overall, 28% (n=38) of respondents in England had a biopsy, 20% (n=27) of a kidney growth and 8% (n=11) 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, 38% (n=52) of respondents in England indicated that their tissue was looked at after they had surgery to remove it. Globally, this was 36% (n=664) of respondents. A further 33% (n=46) reported that they were never offered a biopsy – 17% (n=314) globally while 1% (n=2) were offered a biopsy but refused the procedure (3%, n=47 globally).

Of the respondents in England who did not have a biopsy, 54% (n=53) 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 England, over 60% of respondents agreed/strongly agreed that they understood the following:

- surgical options (90%, n=121 of respondents, globally 90%, n=1637)
- active surveillance (77%, n=101 of respondents, globally 75%, n=1272)
- palliative care (74%, n=84 of respondents, globally 65%, n=985)
- immunotherapy options (67%, n=78 of respondents, globally 69%, n=1079)
- the role of nutrition/lifestyle on their wellbeing (67%, n=90 of respondents, globally 78%, n=1393)
- targeted therapy options (64%, n=74 of respondents, globally 71%, n=1140)

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

- ablative therapy options (39%, n=41 of respondents, globally 19%, n=293)
- local guidelines for kidney cancer care (37%, n=50 of respondents, globally 15%, n=248)
- local guidelines for kidney cancer follow up (26%, n=35 of respondents, globally 12%, n=209)
- complementary therapies (e.g., meditation, etc.) (25%, n=31 of respondents, globally 16%, n=272)
- radiation therapy options (24%, n=26 of respondents, globally 11%, n=172)

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

62% of respondents in England (n=84) indicated that no one spoke to them about cancer clinical trials. Of those that did discuss cancer clinical trials, 26% (n=13) indicated that clinical trials had been discussed with a patient organisation/support group, and 84% (n=42) said with a doctor/nurse.

Taking part in clinical trial

27% (n=37) of respondents who were residents of England were invited to participate in a cancer clinical trial, compared with 31% (n=549) globally. Of these, 68% (n=32) went on to participate in a cancer clinical trial and 78% (n=25) reported being satisfied with their overall experience. Only one person was dissatisfied with their experience.

Respondents were asked how likely it is that they would participate in a cancer clinical trial if they had been or were yet to be invited. The majority of respondents (73%, n=73) 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.

51% of respondents in England (n=69) self-reported that they were insufficiently active/completely sedentary. This is compared with 46% of respondents globally (n=830). 40% of respondents (n=53) reported physical levels to be within guidelines (150-299 minutes of physical activity per week) while 9% (n=12) described their level of physical activity as above guidelines of more than 300 minutes per week.

Psychosocial wellbeing

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

- 55% (n=74) said that they very often/always had the fear of recurrence, 55% (n=1003) globally
- 43% (n=58) reported that they very often/always felt disease-specific anxiety, compared with 49% (n=904) globally
- 40% (n=55) of respondents reported that they very often/always felt general anxiety, compared with 43% (n=792) globally

Sources of support

43% (n=54) of respondents in England 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. 79% of respondents (n=107) 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, 60% (n=64) 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 England, please see the Frequency Tables in Appendix 2.

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[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 England: *(Definitions from Graffigna et al., 2015)*

- 5% (n=7) of respondents residing in England 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.

- 26% (n=35) of respondents residing in England 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.

- 48% (n=65) of respondents residing in England 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.

- 21% (n=29) of respondents residing in England 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 England 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 – England
2. Frequency Tables – England
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

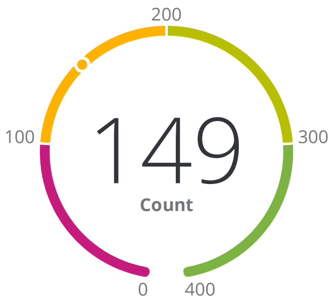
  Country specific reports where respondent numbers are greater or equal to 100. These include:

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

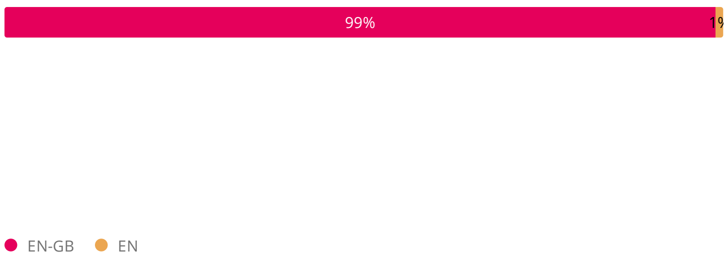
Appendix 1: Graphical Results - United Kingdom - England

About the respondents

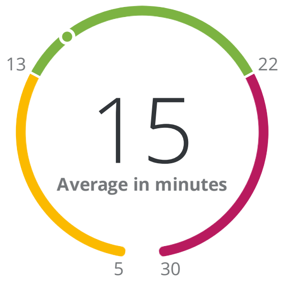
Response count



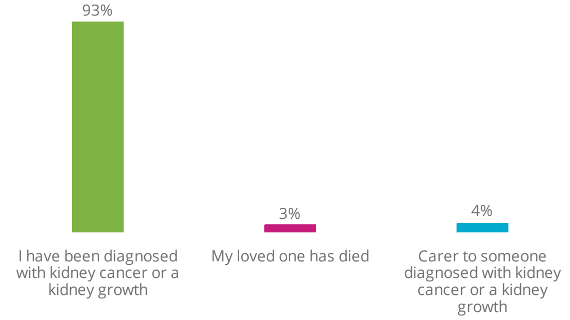
Responses per language 149 Responses



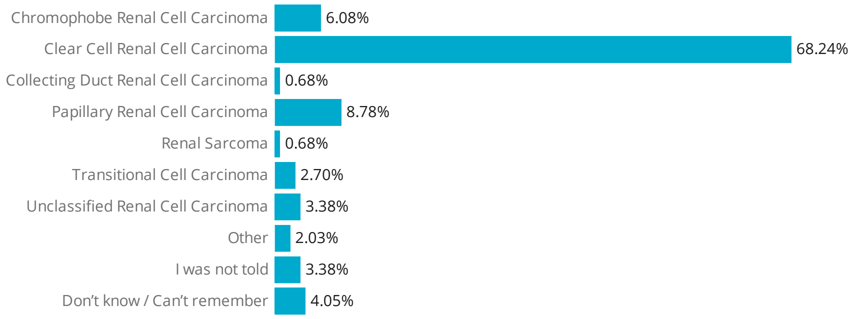
Average of minutes per response
147 Responses



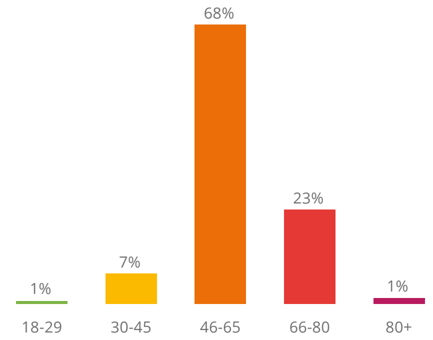
Described experience with kidney cancer 149 Responses



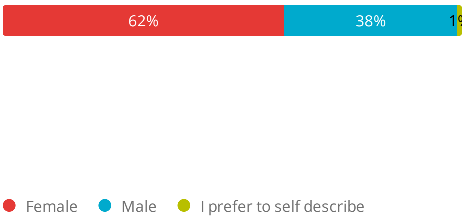
Sub-type of kidney cancer 148 Responses



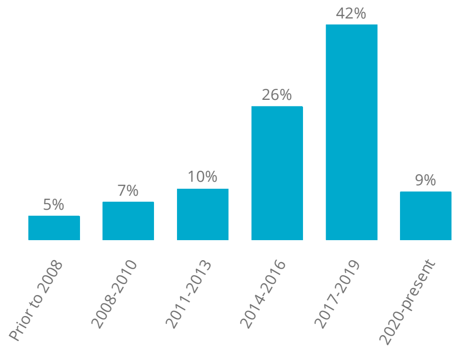
Age 149 Responses



Gender 149 Responses



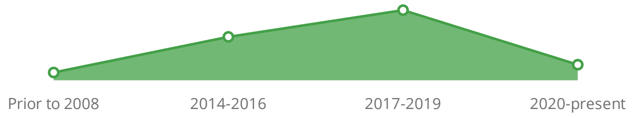
Diagnosis Year 149 Responses



Appendix 1: Graphical Results - United Kingdom - England

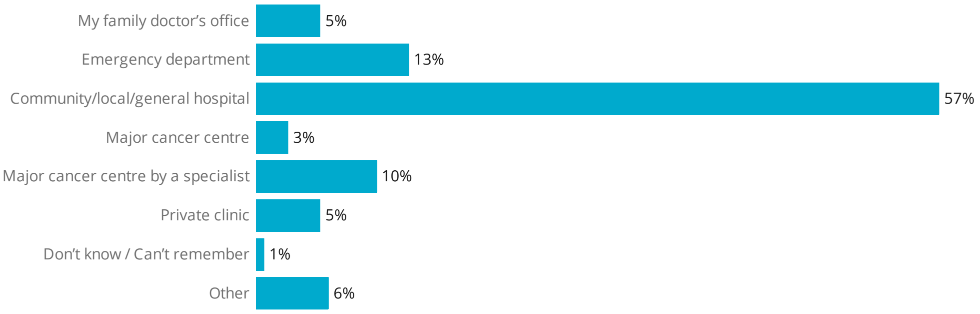
Diagnosis

Diagnosis Year **149** Responses

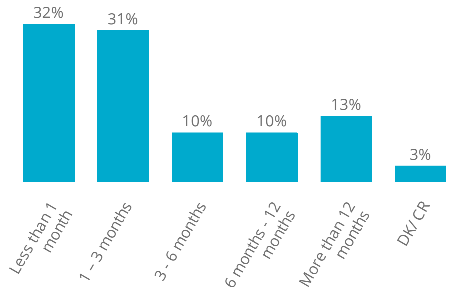


When first diagnosed were you told what subtype? **149** Responses

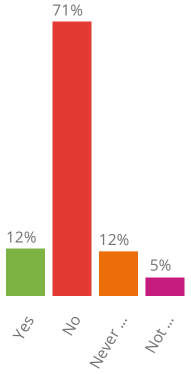
First correctly diagnosed **149** Responses



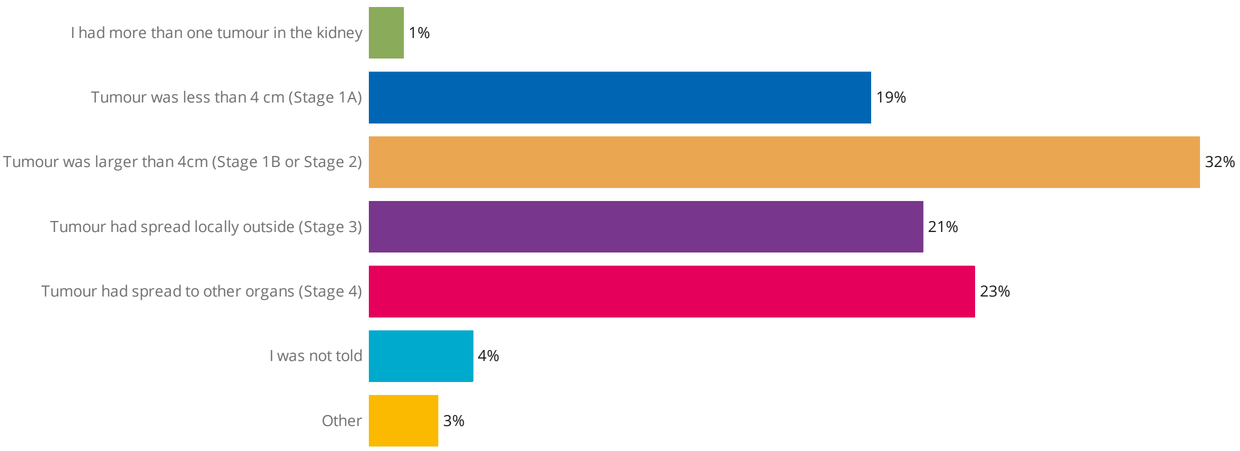
How long was it from the time you first thought something might be wrong with you to being CORRECTLY diagnosed? **149** Responses



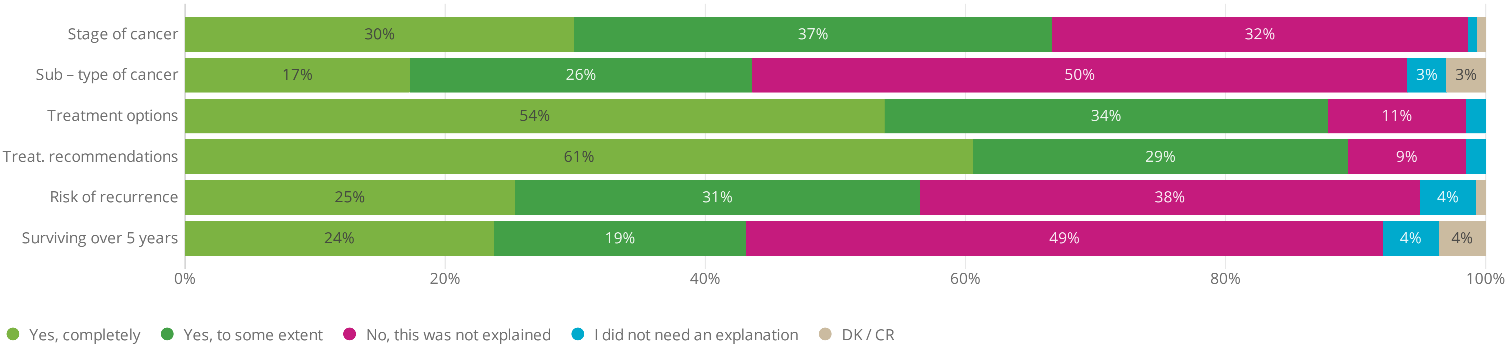
Did you ever seek a second opinion with a kidney cancer expert? **147** Responses



What stage when first diagnosed? **149** Responses



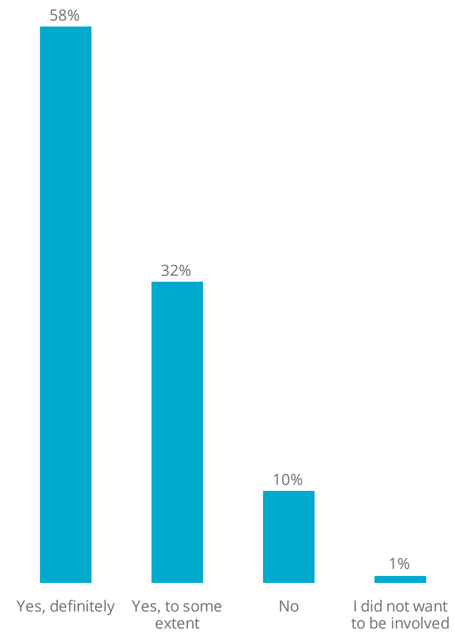
AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? **148** Responses



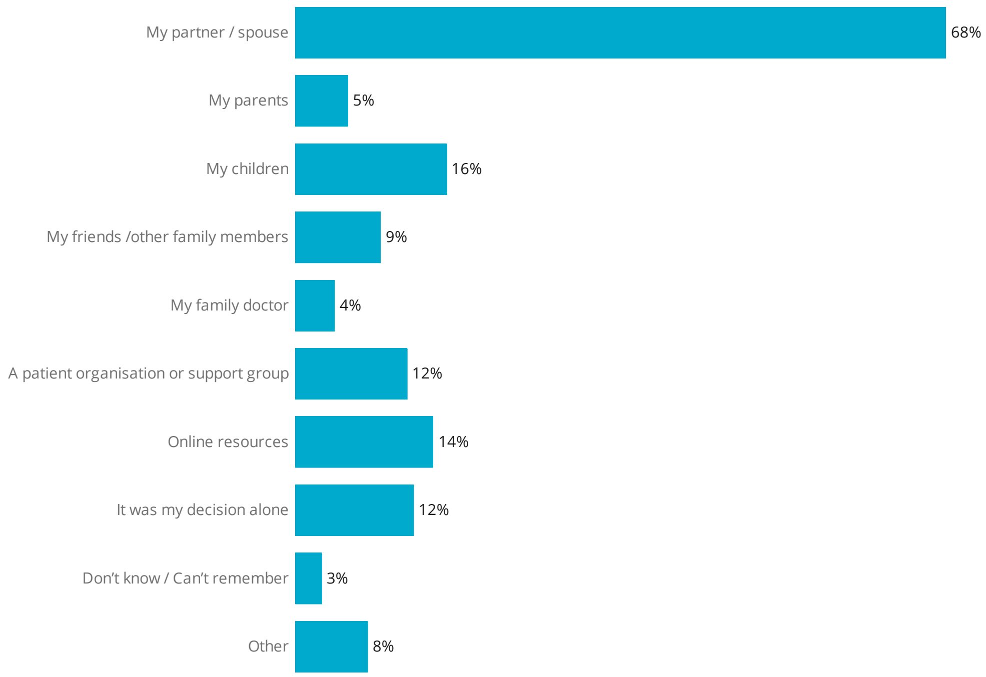
Appendix 1: Graphical Results - United Kingdom - England

Developing a treatment plan

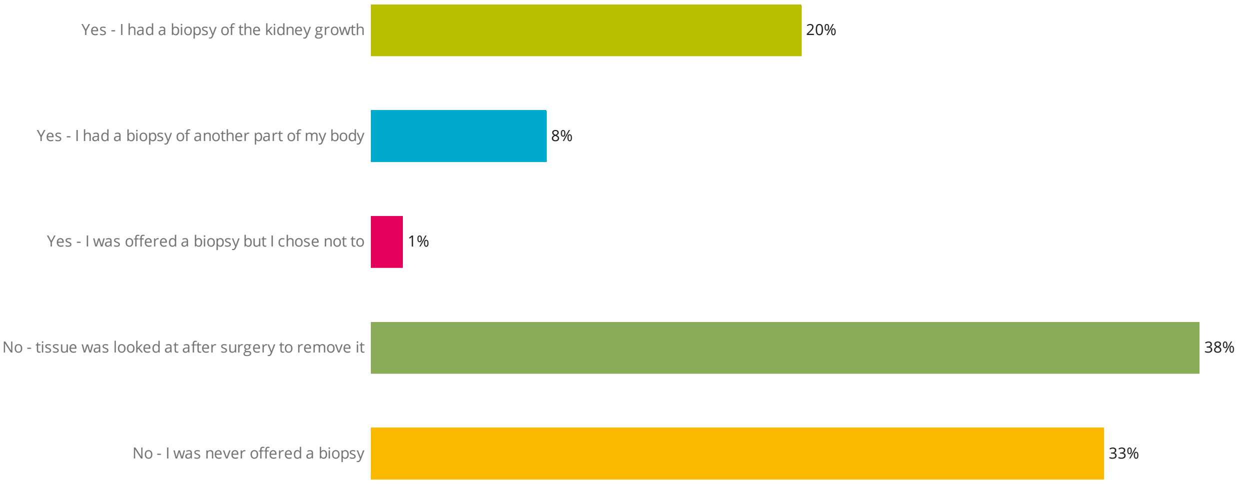
Were you involved as much as you wanted to be in decisions about your treatment plan? 146 Responses



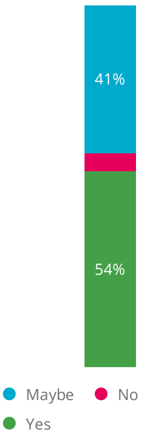
Who or what else helped you make decisions about your treatment plan? 146 Responses



Have you ever been offered a biopsy of some part of your body where kidney cancer was thought to be? 138 Responses



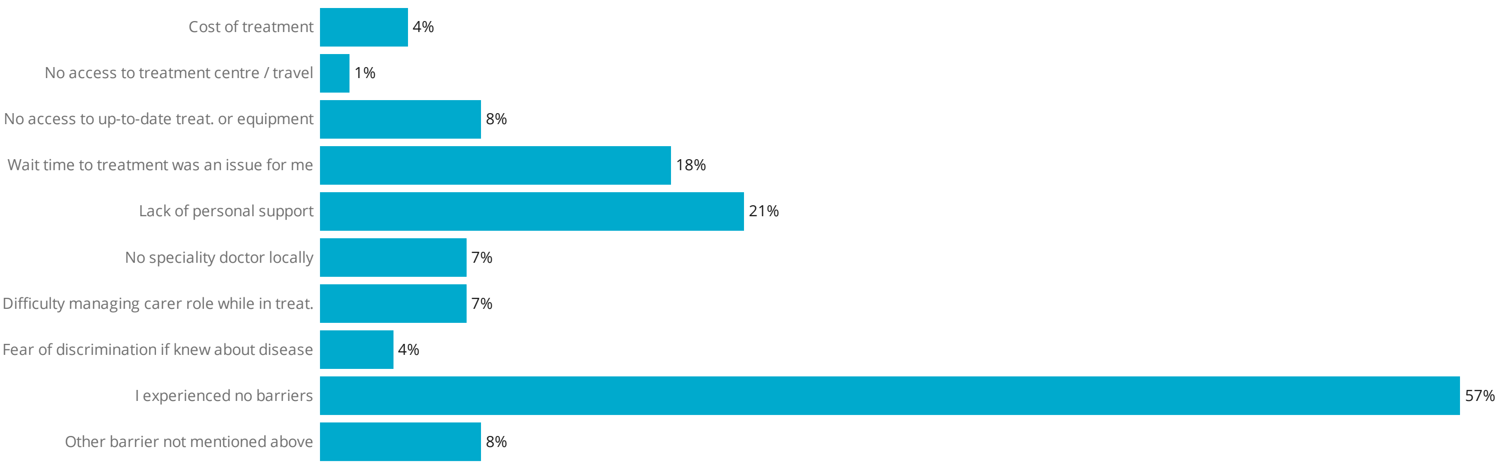
Would you be willing to have a biopsy in the future if necessary? 98 Responses



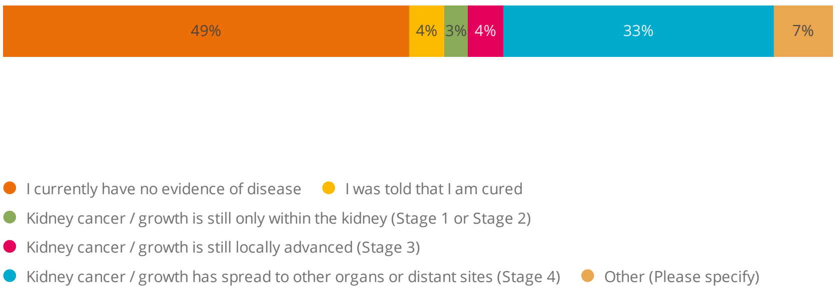
Appendix 1: Graphical Results
- United Kingdom - England

Your care and treatment & your care today

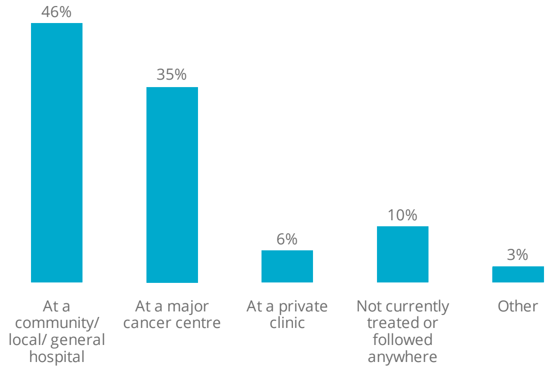
Which barriers (if any) have you experienced in receiving treatment for your kidney cancer or kidney growth? 137 Responses



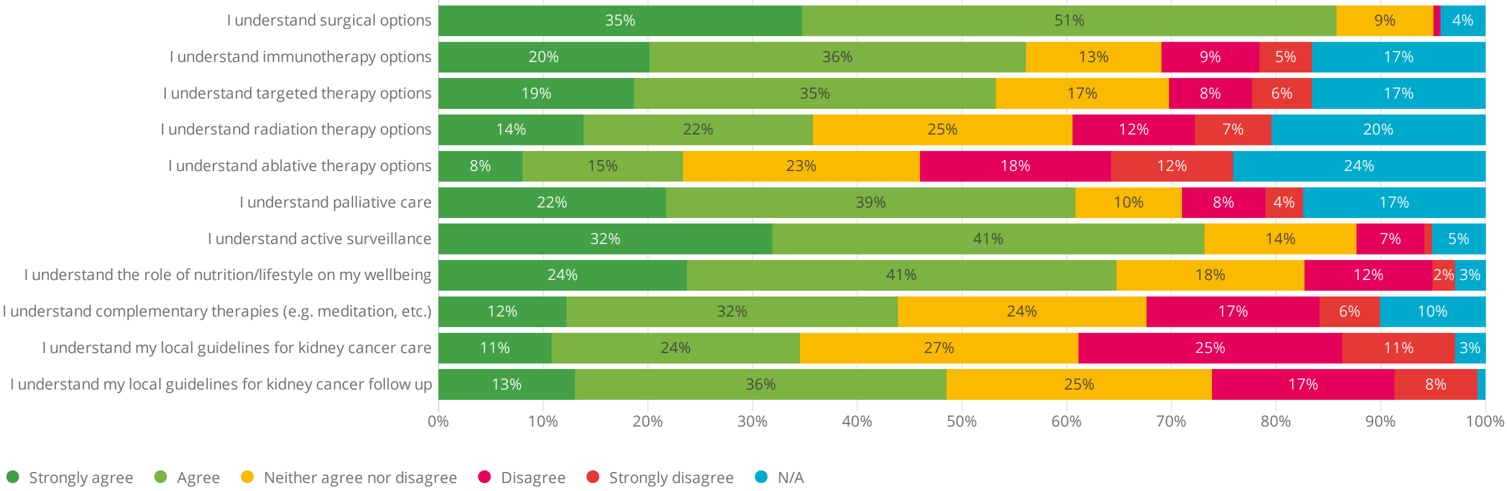
Which of the following best describes your stage of kidney cancer or kidney growth TODAY? 141 Responses



Where are you CURRENTLY being treated or followed? 140 Responses



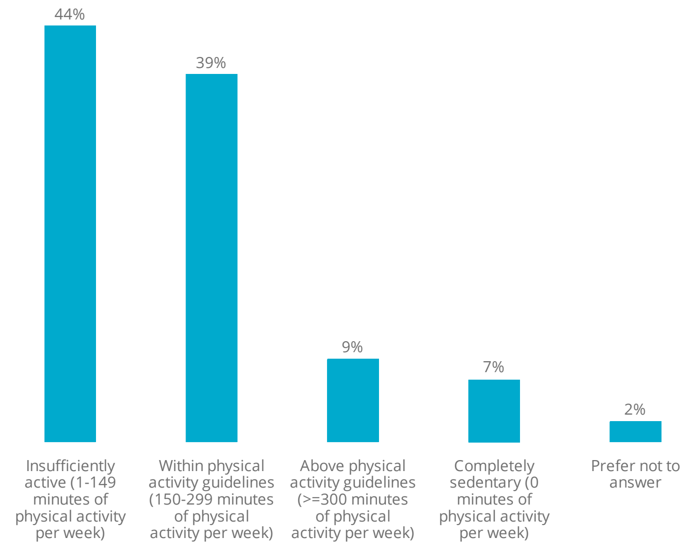
To what extent do you agree or disagree with the following statements?



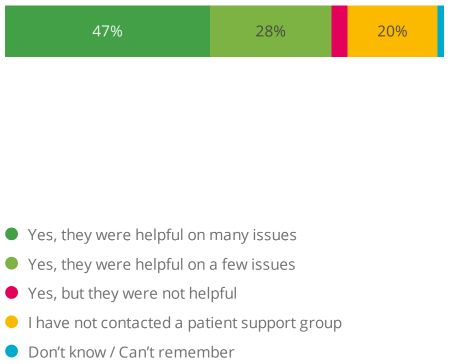
Appendix 1: Graphical Results - United Kingdom - England

Quality of life

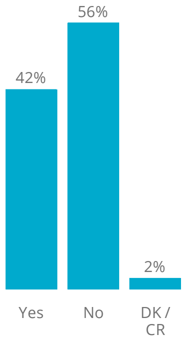
Current level of leisure-time physical activity 137 Responses



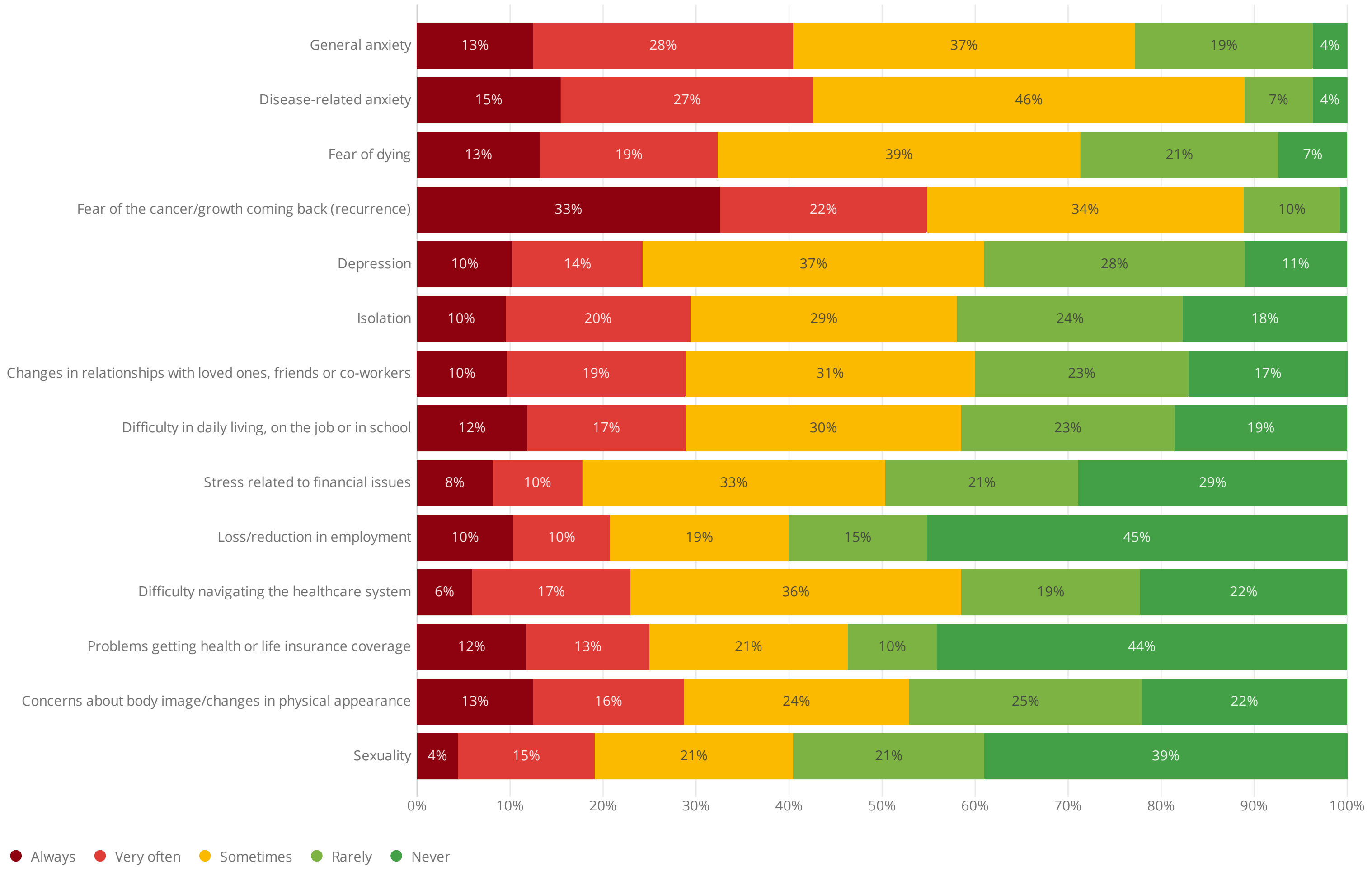
Have you ever used a patient support group (either in person or online) to help you with your kidney cancer / growth? 137 Responses



Have you ever talked to your doctor or to any other healthcare professional about any of these concerns? 129 Responses



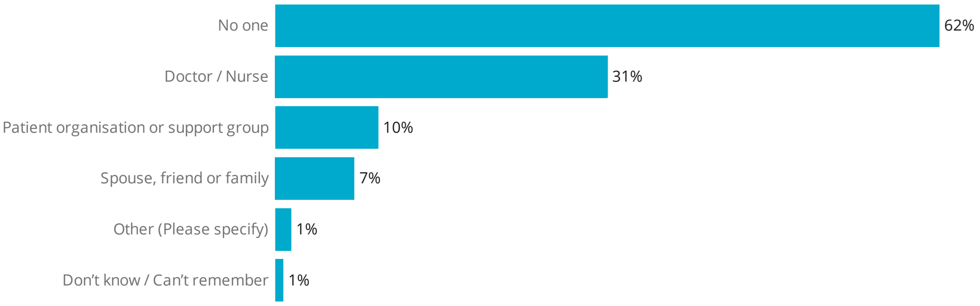
How often have the following impacted your sense of emotional well-being since your diagnosis?



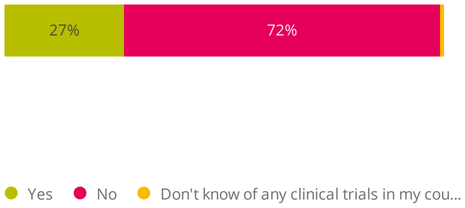
Appendix 1: Graphical Results - United Kingdom - England

Cancer clinical trials

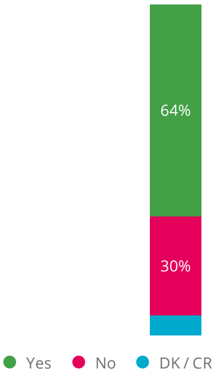
Who, if anyone, has discussed cancer clinical trials with you? **135** Responses



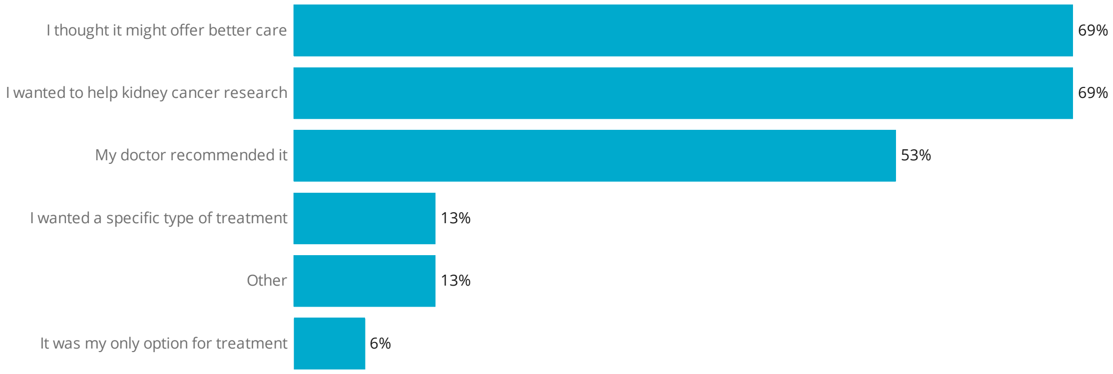
Have you ever been invited to participate in a cancer clinical trial? **136** Responses



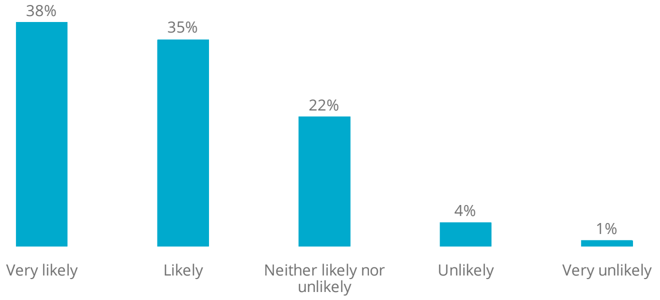
Did you agree to participate in the cancer clinical trial? **50** Responses



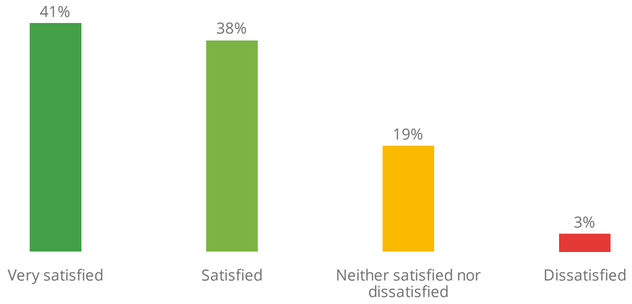
Why did you agree to participate? **32** Responses



If you had been or were invited, how likely is it that you would participate in a cancer clinical trial? **100** Responses



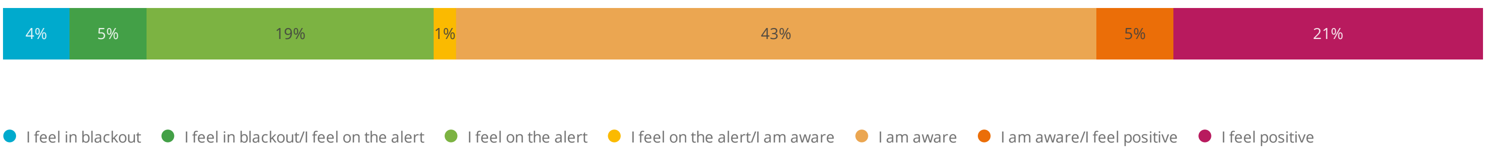
How satisfied were you overall with your cancer clinical trial experience? **32** Responses



Appendix 1: Graphical Results
- United Kingdom - England

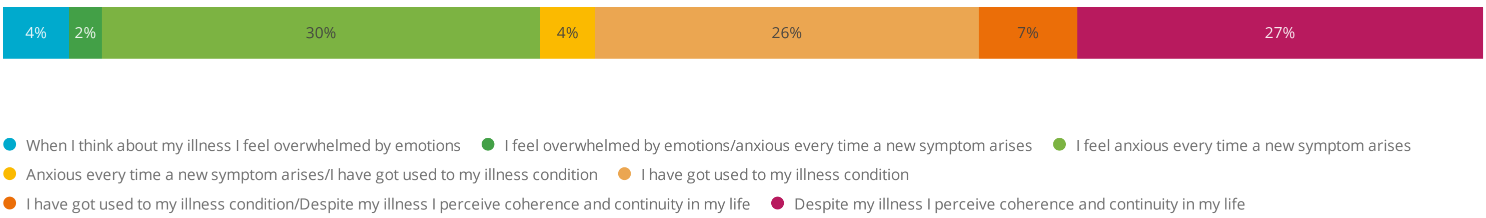
Patient Health Engagement scale from the Università Cattolica del Sacro Cuore

Thinking about my health status... 134 Responses

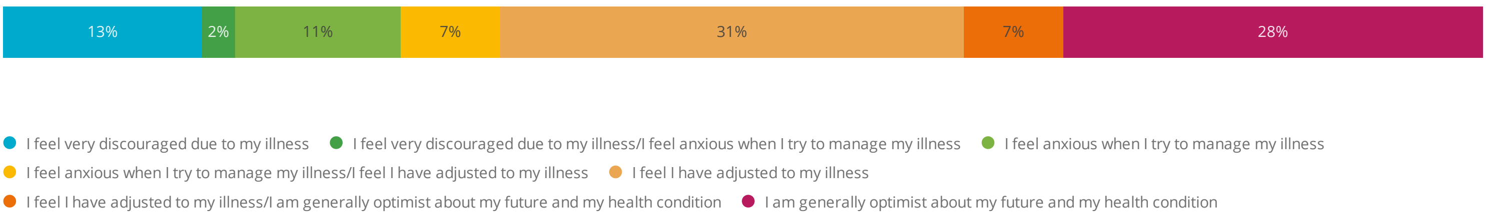


Thinking about my health status... 131 Responses

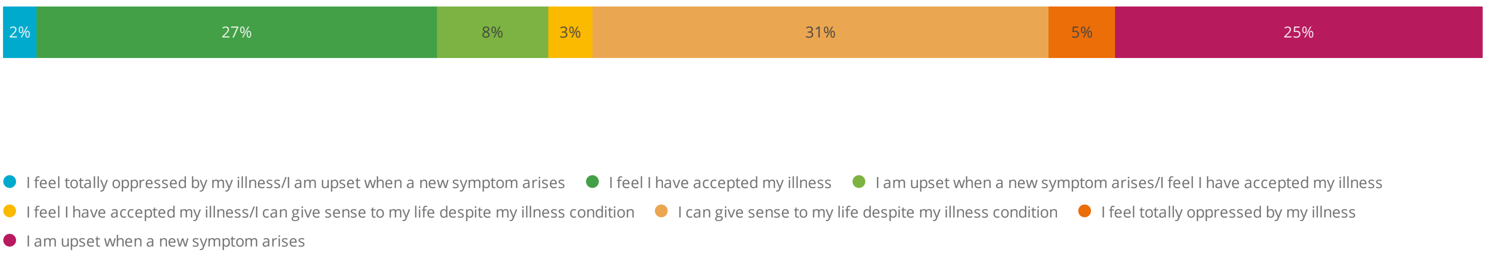
Thinking about my health status... 135 Responses



Thinking about my health status... 134 Responses



Thinking about my health status... 133 Responses



Appendix 2: Frequency Tables - United Kingdom - England

About the respondents

About respondent 149 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	138	93%
I am a carer or caregiver to someone who has been diagnosed with kidney cancer or a kidney growth	6	4%
My loved one has died	5	3%
Total	149	100%

Sub-type of kidney cancer 148 Responses

Q2 - What sub-type of kidney cancer do you have?	Count ▲	Percent
Clear Cell Renal Cell Carcinoma	101	68%
Papillary Renal Cell Carcinoma	13	9%
Chromophobe Renal Cell Carcinoma	9	6%
Don't know / Can't remember	6	4%
Unclassified Renal Cell Carcinoma	5	3%
I was not told	5	3%
Transitional Cell Carcinoma (Urothelial Carcinoma)	4	3%
Other	3	2%
Renal Sarcoma (NOT Renal Cell Carcinoma with Sarcomatoid Appearance)	1	1%
Collecting Duct Renal Cell Carcinoma (Bellini Duct)	1	1%
Total	148	100%

Age 149 Responses

Q4 - What is your age now?	Count ▲	Percent
46-65	101	68%
66-80	34	23%
30-45	11	7%
80+	2	1%
18-29	1	1%
Total	149	100%

Gender 149 Responses

Q5 - What is your gender?	Count ▲	Percent
Female	92	62%
Male	56	38%
I prefer to self describe	1	1%
Total	149	100%

Country of residence 149 Responses

Q3 - In which country do you currently reside?	Count	Percent
United Kingdom - England	149	100%
Total	149	100%

Appendix 2: Frequency Tables - United Kingdom - England

Diagnosis

Diagnosis Year 149 Responses

Q6 - In what year were you diagnosed?	Count ▲	Percent
2017-2019	63	42%
2014-2016	39	26%
2011-2013	15	10%
2020-present	14	9%
2008-2010	11	7%
Prior to 2008	7	5%
Total	149	100%

First correctly diagnosed 149 Responses

Q7 - Where was your kidney growth FIRST CORRECTLY DIAGNOSED?	Count ▲	Percent
Community/local/general hospital	85	57%
Emergency department	19	13%
Major cancer centre by a specialist	15	10%
Other	9	6%
My family doctor's office	8	5%
Private clinic	8	5%
Major cancer centre	4	3%
Don't know / Can't remember	1	1%
Total	149	100%

When first diagnosed were you told what subtype? 149 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	95	64%
Yes	42	28%
Not sure	12	8%
Total	149	100%

When first diagnosed were you told what subtype? - Positive Score 137 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	95	69%
Yes	42	31%
Total	137	100%

What stage when first diagnosed? 149 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)	48	32%
Tumour had spread to other organs (Stage 4)	35	23%
Tumour had spread locally outside (Stage 3)	32	21%
Tumour was less than 4 cm (Stage 1A)	29	19%
I was not told	6	4%
Other	4	3%
I had more than one tumour in the kidney	2	1%
Total	156	105%

Diagnosis

How long to correct diagnosis? 149 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	48	32%
1 – 3 months	46	31%
More than 12 months	20	13%
6 months - 12 months	15	10%
3 - 6 months	15	10%
DK/ CR	5	3%
Total	149	100%

How long to correct diagnosis? - Positive Score 144 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	48	33%
1 – 3 months	46	32%
More than 12 months	20	14%
6 months - 12 months	15	10%
3 - 6 months	15	10%
Total	144	100%

Explanation at diagnosis - Stage of cancer 147 Responses

Q11a - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Stage of cancer	Count ▲	Percent
Yes, to some extent	54	37%
No, this was not explained	47	32%
Yes, completely	44	30%
I did not need an explanation	1	1%
Don't know / can't remember	1	1%
Total	147	100%

Explanation at diagnosis - Stage of cancer - Positive Score 145 Responses

Q11a+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Stage of cancer	Count ▲	Percent
Yes, to some extent	54	37%
No, this was not explained	47	32%
Yes, completely	44	30%
Total	145	100%

Explanation at diagnosis - Subtype of cancer 133 Responses

Q11b - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Subtype of cancer	Count ▲	Percent
No, this was not explained	67	50%
Yes, to some extent	35	26%
Yes, completely	23	17%
I did not need an explanation	4	3%
Don't know / can't remember	4	3%
Total	133	100%

Explanation at diagnosis - Subtype of cancer - Positive Score 125 Responses

Q11b+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Subtype of cancer	Count ▲	Percent
No, this was not explained	67	54%
Yes, to some extent	35	28%
Yes, completely	23	18%
Total	125	100%

Diagnosis

Explanation at diagnosis - Treatment options 132 Responses

Q11c - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment options	Count ▲	Percent
Yes, completely	71	54%
Yes, to some extent	45	34%
No, this was not explained	14	11%
I did not need an explanation	2	2%
Total	132	100%

Explanation at diagnosis - Treatment options - Positive Score 130 Responses

Q11c+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment options	Count ▲	Percent
Yes, completely	71	55%
Yes, to some extent	45	35%
No, this was not explained	14	11%
Total	130	100%

Explanation at diagnosis - Treatment recommendations 132 Responses

Q11d - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment recommendations	Count ▲	Percent
Yes, completely	80	61%
Yes, to some extent	38	29%
No, this was not explained	12	9%
I did not need an explanation	2	2%
Total	132	100%

Explanation at diagnosis - Treatment recommendations - Positive Score 130 Responses

Q11d+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Treatment recommendations	Count ▲	Percent
Yes, completely	80	62%
Yes, to some extent	38	29%
No, this was not explained	12	9%
Total	130	100%

Explanation at diagnosis - Risk of recurrence 138 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	53	38%
Yes, to some extent	43	31%
Yes, completely	35	25%
I did not need an explanation	6	4%
Don’t know / can’t remember	1	1%
Total	138	100%

Explanation at diagnosis - Risk of recurrence - Positive Score 131 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	53	40%
Yes, to some extent	43	33%
Yes, completely	35	27%
Total	131	100%

Diagnosis

Explanation at diagnosis - Likelihood of surviving beyond 5 yrs 139 Responses

Q11f - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Likelihood of surviving beyond 5 yrs	Count ▲	Percent
No, this was not explained	68	49%
Yes, completely	33	24%
Yes, to some extent	27	19%
I did not need an explanation	6	4%
Don't know / can't remember	5	4%
Total	139	100%

Explanation at diagnosis - Likelihood of surviving beyond 5 yrs - Positive Score 128 Responses

Q11f+ - AT THE TIME OF DIAGNOSIS, were the following explained in a way you could understand? - Likelihood of surviving beyond 5 yrs	Count ▲	Percent
No, this was not explained	68	53%
Yes, completely	33	26%
Yes, to some extent	27	21%
Total	128	100%

Second opinion 147 Responses

Q12 - Did you ever seek a second opinion with a kidney cancer expert?	Count ▲	Percent
No	105	71%
Yes	18	12%
Never considered it	17	12%
Not available to me	7	5%
Total	147	100%

Developing a treatment plan

Involvement in treatment plan 146 Responses

Q13 - Were you involved as much as you wanted to be in decisions about your treatment plan?	Count ▲	Percent
Yes, definitely	85	58%
Yes, to some extent	46	32%
No	14	10%
I did not want to be involved	1	1%
Total	146	100%

Involvement in treatment plan - Positive Score 145 Responses

Q13+ - Were you involved as much as you wanted to be in decisions about your treatment plan?	Count ▲	Percent
Yes, definitely	85	59%
Yes, to some extent	46	32%
No	14	10%
Total	145	100%

Support in treatment plan decisions 146 Responses

Q14 - Who or what else helped you make decisions about your treatment plan? (PLEASE CHOOSE ALL THAT APPLY)	Count ▲	Percent
My partner / spouse	99	68%
My children	23	16%
Online resources	21	14%
It was my decision alone	18	12%
A patient organisation or support group	17	12%
My friends /other family members	13	9%
Other	11	8%
My parents	8	5%
My family doctor	6	4%
Don't know / Can't remember	4	3%
Total	220	151%

Barriers to treatment 137 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	78	57%
Lack of personal support	29	21%
Wait time to treatment was an issue for me	24	18%
Other barrier not mentioned above	11	8%
No access to up-to-date treat. or equipment	11	8%
No speciality doctor locally	10	7%
Difficulty managing carer role while in treat.	10	7%
Cost of treatment	6	4%
Fear of discrimination if knew about disease	5	4%
No access to treatment centre / travel	2	1%
Total	186	136%

Appendix 2: Frequency Tables - United Kingdom - England

Your care and treatment & your care today

Stage of kidney cancer or kidney growth TODAY 141 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	69	49%
Kidney cancer / growth has spread to other organs or distant sites (Stage 4)	46	33%
Other (Please specify)	10	7%
Kidney cancer / growth is still locally advanced (Stage 3)	6	4%
I was told that I am cured	6	4%
Kidney cancer / growth is still only within the kidney (Stage 1 or Stage 2)	4	3%
Total	141	100%

Treatment TODAY 140 Responses

Q17 - Where are you CURRENTLY being treated or followed?	Count ▲	Percent
At a community/ local/ general hospital	65	46%
At a major cancer centre	49	35%
Not currently treated or followed anywhere	14	10%
At a private clinic	8	6%
Other	4	3%
Total	140	100%

Understanding of care/treatment - Surgical options 141 Responses

Q18a - I understand surgical options	Count ▲	Percent
Agree	72	51%
Strongly agree	49	35%
Neither agree nor disagree	13	9%
N/A	6	4%
Disagree	1	1%
Total	141	100%

Understanding of care/treatment - Surgical options - Positive Score 135 Responses

Q18a+ - I understand surgical options	Count ▲	Percent
Agree	72	53%
Strongly agree	49	36%
Neither agree nor disagree	13	10%
Disagree	1	1%
Total	135	100%

Understanding of care/treatment - Immunotherapy options 139 Responses

Q18b - I understand immunotherapy options	Count ▲	Percent
Agree	50	36%
Strongly agree	28	20%
N/A	23	17%
Neither agree nor disagree	18	13%
Disagree	13	9%
Strongly disagree	7	5%
Total	139	100%

Understanding of care/treatment - Immunotherapy options - Positive Score 116 Responses

Q18b+ - I understand immunotherapy options	Count ▲	Percent
Agree	50	43%
Strongly agree	28	24%
Neither agree nor disagree	18	16%
Disagree	13	11%
Strongly disagree	7	6%
Total	116	100%

Your care and treatment & your care today

Understanding of care/treatment - Targeted therapy options 139 Responses

Q18c - I understand targeted therapy options	Count ▲	Percent
Agree	48	35%
Strongly agree	26	19%
Neither agree nor disagree	23	17%
N/A	23	17%
Disagree	11	8%
Strongly disagree	8	6%
Total	139	100%

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

Q18c+ -I understand targeted therapy options	Count ▲	Percent
Agree	48	41%
Strongly agree	26	22%
Neither agree nor disagree	23	20%
Disagree	11	9%
Strongly disagree	8	7%
Total	116	100%

Understanding of care/treatment - Radiation therapy options 137 Responses

Q18d - I understand radiation therapy options	Count ▲	Percent
Neither agree nor disagree	34	25%
Agree	30	22%
N/A	28	20%
Strongly agree	19	14%
Disagree	16	12%
Strongly disagree	10	7%
Total	137	100%

Understanding of care/treatment - Radiation therapy options - Positive Score 109 Responses

Q18d+ - I understand radiation therapy options	Count ▲	Percent
Neither agree nor disagree	34	31%
Agree	30	28%
Strongly agree	19	17%
Disagree	16	15%
Strongly disagree	10	9%
Total	109	100%

Understanding of care/treatment - Ablative therapy options 137 Responses

Q18e - I understand ablative therapy options	Count ▲	Percent
N/A	33	24%
Neither agree nor disagree	31	23%
Disagree	25	18%
Agree	21	15%
Strongly disagree	16	12%
Strongly agree	11	8%
Total	137	100%

Understanding of care/treatment - Ablative therapy options - Positive Score 104 Responses

Q18e+ - I understand ablative therapy options	Count ▲	Percent
Neither agree nor disagree	31	30%
Disagree	25	24%
Agree	21	20%
Strongly disagree	16	15%
Strongly agree	11	11%
Total	104	100%

Your care and treatment & your care today

Understanding of care/treatment - Palliative 138 Responses

Q18f - I understand palliative care	Count ▲	Percent
Agree	54	39%
Strongly agree	30	22%
N/A	24	17%
Neither agree nor disagree	14	10%
Disagree	11	8%
Strongly disagree	5	4%
Total	138	100%

Understanding of care/treatment - Palliative - Positive Score 114 Responses

Q18f+ - I understand palliative care	Count ▲	Percent
Agree	54	47%
Strongly agree	30	26%
Neither agree nor disagree	14	12%
Disagree	11	10%
Strongly disagree	5	4%
Total	114	100%

Understanding of care/treatment - Active Surveillance 138 Responses

Q18g -I understand active surveillance	Count ▲	Percent
Agree	57	41%
Strongly agree	44	32%
Neither agree nor disagree	20	14%
Disagree	9	7%
N/A	7	5%
Strongly disagree	1	1%
Total	138	100%

Understanding of care/treatment - Active Surveillance - Positive Score 131 Responses

Q18g+ -I understand active surveillance	Count ▲	Percent
Agree	57	44%
Strongly agree	44	34%
Neither agree nor disagree	20	15%
Disagree	9	7%
Strongly disagree	1	1%
Total	131	100%

Understanding of care/treatment - Role of nutrition/lifestyle 139 Responses

Q18h - I understand the role of nutrition/lifestyle on my wellbeing	Count ▲	Percent
Agree	57	41%
Strongly agree	33	24%
Neither agree nor disagree	25	18%
Disagree	17	12%
N/A	4	3%
Strongly disagree	3	2%
Total	139	100%

Understanding of care/treatment - Role of nutrition/lifestyle - Positive Score 135 Responses

Q18h+ - I understand the role of nutrition/lifestyle on my wellbeing	Count ▲	Percent
Agree	57	42%
Strongly agree	33	24%
Neither agree nor disagree	25	19%
Disagree	17	13%
Strongly disagree	3	2%
Total	135	100%

Your care and treatment & your care today

Understanding of care/treatment - Complementary therapies 139 Responses

Q18i - I understand complementary therapies (e.g. meditation, etc.)	Count ▲	Percent
Agree	44	32%
Neither agree nor disagree	33	24%
Disagree	23	17%
Strongly agree	17	12%
N/A	14	10%
Strongly disagree	8	6%
Total	139	100%

Understanding of care/treatment - Complementary therapies - Positive Score 125 Responses

Q18i+ - I understand complementary therapies (e.g. meditation, etc.)	Count ▲	Percent
Agree	44	35%
Neither agree nor disagree	33	26%
Disagree	23	18%
Strongly agree	17	14%
Strongly disagree	8	6%
Total	125	100%

Understanding of care/treatment - Local guidelines for care 139 Responses

Q18j - I understand my local guidelines for kidney cancer care	Count ▲	Percent
Neither agree nor disagree	37	27%
Disagree	35	25%
Agree	33	24%
Strongly disagree	15	11%
Strongly agree	15	11%
N/A	4	3%
Total	139	100%

Understanding of care/treatment - Local guidelines for care - Positive Score 135 Responses

Q18j+ - I understand my local guidelines for kidney cancer care	Count ▲	Percent
Neither agree nor disagree	37	27%
Disagree	35	26%
Agree	33	24%
Strongly disagree	15	11%
Strongly agree	15	11%
Total	135	100%

Understanding of care/treatment - Local guidelines for follow up 138 Responses

Q18k - I understand my local guidelines for kidney cancer follow up	Count ▲	Percent
Agree	49	36%
Neither agree nor disagree	35	25%
Disagree	24	17%
Strongly agree	18	13%
Strongly disagree	11	8%
N/A	1	1%
Total	138	100%

Understanding of care/treatment - Local guidelines for follow up - Positive Score 137 Responses

Q18k+ - I understand my local guidelines for kidney cancer follow up	Count ▲	Percent
Agree	49	36%
Neither agree nor disagree	35	26%
Disagree	24	18%
Strongly agree	18	13%
Strongly disagree	11	8%
Total	137	100%

Your care and treatment & your care today

Biopsy experience 138 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	52	38%
No - I was never offered a biopsy	46	33%
Yes - I had a biopsy of the kidney growth	27	20%
Yes - I had a biopsy of another part of my body	11	8%
Yes - I was offered a biopsy but I chose not to	2	1%
Total	138	100%

Biopsy 98 Responses

Q20 - Would you be willing to have a biopsy in the future if necessary?	Count ▲	Percent
Yes	53	54%
Maybe	40	41%
No	5	5%
Total	98	100%

Quality of life

Physical activity 137 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)	60	44%
Within physical activity guidelines (150-299 minutes of physical activity per week)	53	39%
Above physical activity guidelines (>=300 minutes of physical activity per week)	12	9%
Completely sedentary (0 minutes of physical activity per week)	9	7%
Prefer not to answer.	3	2%
Total	137	100%

Physical activity - Positive Score 134 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)	60	45%
Within physical activity guidelines (150-299 minutes of physical activity per week)	53	40%
Above physical activity guidelines (≥300 minutes of physical activity per week)	12	9%
Completely sedentary (0 minutes of physical activity per week)	9	7%
Total	134	100%

Emotional well-being - General anxiety 136 Responses

Q22a - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Sometimes	50	37%
Very often	38	28%
Rarely	26	19%
Always	17	13%
Never	5	4%
Total	136	100%

Emotional well-being - Disease related anxiety 136 Responses

Q22b - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Sometimes	63	46%
Very often	37	27%
Always	21	15%
Rarely	10	7%
Never	5	4%
Total	136	100%

Emotional well-being - Fear of dying 136 Responses

Q22c - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Sometimes	53	39%
Rarely	29	21%
Very often	26	19%
Always	18	13%
Never	10	7%
Total	136	100%

Emotional well-being - Fear of cancer/growth coming back 135 Responses

Q22d - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Sometimes	46	34%
Always	44	33%
Very often	30	22%
Rarely	14	10%
Never	1	1%
Total	135	100%

Quality of life

Emotional well-being - Depression 136 Responses

Q22e - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Sometimes	50	37%
Rarely	38	28%
Very often	19	14%
Never	15	11%
Always	14	10%
Total	136	100%

Emotional well-being - Isolation 136 Responses

Q22f - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Sometimes	39	29%
Rarely	33	24%
Very often	27	20%
Never	24	18%
Always	13	10%
Total	136	100%

Emotional well-being - Changes in relationships 135 Responses

Q22g - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Sometimes	42	31%
Rarely	31	23%
Very often	26	19%
Never	23	17%
Always	13	10%
Total	135	100%

Emotional well-being - Difficulty in daily living 135 Responses

Q22h - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Sometimes	40	30%
Rarely	31	23%
Never	25	19%
Very often	23	17%
Always	16	12%
Total	135	100%

Emotional well-being - Stress related to financial issues 135 Responses

Q22i - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Sometimes	44	33%
Never	39	29%
Rarely	28	21%
Very often	13	10%
Always	11	8%
Total	135	100%

Emotional well-being - Loss/reduction in employment 135 Responses

Q22j - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	61	45%
Sometimes	26	19%
Rarely	20	15%
Very often	14	10%
Always	14	10%
Total	135	100%

Quality of life

Emotional well-being - Difficulty navigating the healthcare system

135 Responses

Q22k - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Sometimes	48	36%
Never	30	22%
Rarely	26	19%
Very often	23	17%
Always	8	6%
Total	135	100%

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

136 Responses

Q22l - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	60	44%
Sometimes	29	21%
Very often	18	13%
Always	16	12%
Rarely	13	10%
Total	136	100%

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

136 Responses

Q22m - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Rarely	34	25%
Sometimes	33	24%
Never	30	22%
Very often	22	16%
Always	17	13%

Emotional well-being - Sexuality

136 Responses

Q22n - How often have the following impacted your sense of emotional well-being since your diagnosis?	Count ▲	Percent
Never	53	39%
Sometimes	29	21%
Rarely	28	21%
Very often	20	15%
Always	6	4%
Total	136	100%

Quality of life

Seeking support from medical professional 129 Responses

Q24 - Have you ever talked to your doctor or to any other healthcare professional about any of these concerns?	Count ▲	Percent
No	72	56%
Yes	54	42%
Don't know / Can't remember	3	2%
Total	129	100%

Seeking support from medical professional - Positive Score 126 Responses

Q24+ - Have you ever talked to your doctor or to any other healthcare professional about any of these concerns?	Count ▲	Percent
No	72	57%
Yes	54	43%
Total	126	100%

Seeking support from PSG 137 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
Yes, they were helpful on many issues	64	47%
Yes, they were helpful on a few issues	38	28%
I have not contacted a patient support group	28	20%
Yes, but they were not helpful	5	4%
Don't know / Can't remember	2	1%
Total	137	100%

Seeking support from PSG - Positive Score 135 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
Yes, they were helpful on many issues	64	47%
Yes, they were helpful on a few issues	38	28%
I have not contacted a patient support group	28	21%
Yes, but they were not helpful	5	4%
Total	135	100%

Cancer clinical trials

Discussion with whom 135 Responses

Q26 - Who, if anyone, has discussed cancer clinical trials with you? (PLEASE CHOOSE ALL THAT APPLY)	Count ▲	Percent
No one	84	62%
Doctor / Nurse	42	31%
Patient organisation or support group	13	10%
Spouse, friend or family	10	7%
Other (Please specify)	2	1%
Don’t know / Can’t remember	1	1%
Total	152	113%

Invitation to cancer clinical trials 136 Responses

Q27 - Have you ever been invited to participate in a cancer clinical trial?	Count ▲	Percent
No	98	72%
Yes	37	27%
Don't know of any clinical trials in my country	1	1%
Total	136	100%

Invitation to cancer clinical trials - Positive Score 136 Responses

Q27+ - Have you ever been invited to participate in a cancer clinical trial?	Count ▲	Percent
No	98	72%
Yes	37	27%
I do not know of any clinical trials in my country	1	1%

Actually participated 50 Responses

Q28 - Did you agree to participate in the cancer clinical trial?	Count ▲	Percent
Yes	32	64%
No	15	30%
DK / CR	3	6%
Total	50	100%

Actually participated - Positive Score 47 Responses

Q28+ - Did you agree to participate in the cancer clinical trial?	Count ▲	Percent
Yes	32	68%
No	15	32%
Total	47	100%

Cancer clinical trials

Reasons for participation 32 Responses

Q29 - Why did you agree to participate? (PLEASE CHOOSE ALL THAT APPLY)	Count ▲	Percent
I wanted to help kidney cancer research	22	69%
I thought it might offer better care	22	69%
My doctor recommended it	17	53%
Other	4	13%
I wanted a specific type of treatment	4	13%
It was my only option for treatment	2	6%
Total	71	222%

Satisfaction with overall experience of clinical trial 32 Responses

Q30 - How satisfied were you overall with your cancer clinical trial experience?	Count ▲	Percent
Very satisfied	13	41%
Satisfied	12	38%
Neither satisfied nor dissatisfied	6	19%
Dissatisfied	1	3%
Total	32	100%

Potential participation 100 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	38	38%
Likely	35	35%
Neither likely nor unlikely	22	22%
Unlikely	4	4%
Very unlikely	1	1%
Total	100	100%

Patient Health Engagement scale from the Università Cattolica del Sacro Cuore

Thinking about my health status... 134 Responses

Q32 - I feel in blackout - I feel on alert - I am aware - I feel positive	Count ▲	Percent
I am aware	58	43%
I feel positive	28	21%
I feel on the alert	26	19%
I feel in blackout/I feel on the alert	7	5%
I am aware/I feel positive	7	5%
I feel in blackout	6	4%
I feel on the alert/I am aware	2	1%
Total	134	100%

Thinking about my health status... 131 Responses

Q33 - I feel dazed - I am in alarm - I am conscious - I feel serene	Count ▲	Percent
I am conscious	75	57%
I am in alarm	17	13%
I feel serene	13	10%
I feel dazed	10	8%
I am conscious/I feel serene	7	5%
I am in alarm/I am conscious	6	5%
I feel dazed/I am in alarm	3	2%
Total	131	100%

Thinking about my health status... 135 Responses

Q34 - I am overwhelmed - I feel anxious - I am used - I perceive coherence	Count ▲	Percent
I feel anxious every time a new symptom arises	40	30%
Despite my illness I perceive coherence and continuity in my life	37	27%
I have got used to my illness condition	35	26%
I have got used to my illness condition/Despite my illness I perceive coherence and continuity in my life	9	7%
When I think about my illness I feel overwhelmed by emotions	6	4%
Anxious every time a new symptom arises/I have got used to my illness condition	5	4%
I feel overwhelmed by emotions/anxious every time a new symptom arises	3	2%
Total	135	100%

Thinking about my health status... 134 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	42	31%
I am generally optimist about my future and my health condition	38	28%
I feel very discouraged due to my illness	18	13%
I feel anxious when I try to manage my illness	15	11%
I feel I have adjusted to my illness/I am generally optimist about my future and my health condition	9	7%
I feel anxious when I try to manage my illness/I feel I have adjusted to my illness	9	7%
I feel very discouraged due to my illness/I feel anxious when I try to manage my illness	3	2%
Total	134	100%

Patient Health Engagement scale from the Università Cattolica del Sacro Cuore

Thinking about my health status... 133 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	41	31%
I feel I have accepted my illness	36	27%
I am upset when a new symptom arises	33	25%
I am upset when a new symptom arises/I feel I have accepted my illness	10	8%
I feel totally oppressed by my illness	6	5%
I feel I have accepted my illness/I can give sense to my life despite my illness condition	4	3%
I feel totally oppressed by my illness/I am upset when a new symptom arises	3	2%
Total	133	100%

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