



# **International Kidney Cancer Coalition**

## **Global Patient Survey 2022**

**Country Report – USA**

**August 2023**

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## Foreword

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

To improve collective understanding, the International Kidney Cancer Coalition (IKCC) 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 to administer this programme, including updating the patient questionnaire, with the intention to further explore and benchmark worldwide patient experience. This partnership continued for the 2022 survey iteration.

The survey was published online in 16 languages and promoted through IKCC affiliates and partners, as well as via the IKCC social media and web pages, between September and November 2022. The survey achieved 2213 patient and carer/caregiver responses across 39 countries globally.

This report presents the data from USA.



## USA Key Findings Summary

### Genetic testing

**15%** of patients reported they met the criteria for genetic testing (diagnosed under 46 years old; family history of kidney cancer or bilateral disease) but were not offered genetic testing (Q36)

**37%** reported they had some of the relevant risk factors (diagnosed under 46 years old; family history of kidney cancer or bilateral disease) and were either offered genetic testing or genetic testing had been completed at time of survey (Q36)

### Patient feedback on management of small renal mass

If diagnosed with a small renal mass, **63%** reported they would be willing to participate in Active Surveillance with regular imaging such as ultrasound and CT scans if their doctor recommended it (Q20)

**82%** of respondents would be willing to have a biopsy of a small renal growth if it might change the treatment decision (Q21)

### Surveillance preferences

Following surgery for kidney cancer or kidney growth (Q22):

**25%** would prefer to have regular imaging scans for less than 2 years

**13%** would prefer between 2 and 6 years

**26%** preferred more than 6 years

**30%** would make this decision based on their healthcare team's opinion



## USA Key Findings Summary

### Shared decision-making

**68%** of respondents reported that they were definitely involved as much as they wanted to be in developing their treatment plan (Q13+)

### Understanding of diagnosis and treatment options

**49%** of respondents completely understood treatment options when planning their treatments (Q11\_3+)

**54%** felt that treatment recommendations were completely understood when planning their treatments (Q11\_4+)

**50%** reported that the likelihood of surviving their cancer beyond five years was not explained when planning their treatments (Q11\_6+)

### Understanding of medical care and treatment

**33%** of respondents reported they did not understand adjuvant therapy (treatment aimed at reducing the chance of recurrence after surgery) (Q18\_7+)

### Emotional wellbeing

**14%** felt their sense of emotional well-being since their diagnosis has always been impacted by disease-related anxiety (Q24\_2)

**24%** reported fear of the cancer/growth coming back (recurrence) always impacts their sense of emotional well-being since their diagnosis (Q24\_4)

**5%** reported always feeling their sense of emotional well-being since their diagnosis being impacted by sadness or depression (Q24\_5)

*Please note questions marked with a '+' indicate a derived question, for more information on how these are calculated, see derived questions in the methodology section*



## USA Key Findings Summary

### Support from healthcare professionals

**35%** of respondents reported their doctor or healthcare professional was very helpful when they spoke about their concerns (Q27+)

### Clinical trials

**50%** of respondents reported they had been asked by a health professional to consider participating in a cancer clinical trial (Q30)

**75%** agreed to participate in the cancer clinical trial (Q31)

**59%** reported they were very satisfied or satisfied with their overall experience of the cancer clinical trial (Q33)

*Please note questions marked with a '+' indicate a derived question, for more information on how these are calculated, see derived questions in the methodology section*



## Methodology

### Survey fieldwork

The survey was hosted on the third-party online survey portal Qualtrics. It was administered through an open link and distributed by IKCC global affiliates to patients with kidney cancer or a kidney growth and their caregivers.

The survey was available between 26 September 2022 and 21 November 2022. It was promoted at regular intervals by the IKCC global affiliates and partners, as well as advertised via the IKCC and partner organisation's social media and websites.

### Analysis and reporting

Comparison to global data in this report refers to the 2213 patient and carer/caregiver responses across 39 countries globally.

Please note that there are differences in kidney cancer care provision between countries, as well as differences in the profile of respondents globally. Within each country, respondents were recruited by patient organisations serving different patient populations at varying stages of disease. Therefore, variations in findings across countries may reflect bias in how respondents were accrued. Moreover, method of survey completion differed by country of residence, with some countries primarily conducting interviewer-led surveys, while patients in other countries primarily completed the survey independently. Several cultural differences are expected to be found within the survey findings, such as willingness to disclose information on certain topics. For these reasons, caution should be taken when comparing subgroup results to global data.

### Questionnaire routing

To improve respondent experience, routed questions were used in the survey tool to ensure respondents were only shown questions that were relevant to them. For example: Q30: "Have you ever been asked by a health professional to consider participating in a cancer clinical trial?". Only respondents that answered "Yes" to this question, were directed to Q31: "Did you agree to participate in the cancer clinical trial?". Consequently, some questions were only asked of a subset of respondents. Furthermore, respondents had the ability to leave questions blank. This means that the total number of respondents may fluctuate between questions. Where applicable the total number of respondents, or base size, is indicated with the abbreviation n.



### Derived questions

Some questions were not applicable to all respondents but were not preceded by a filter/routing question. These questions have response options such as “I did not need” or “Don’t know / Can’t remember”. Overall percentages were calculated after removing these non applicable respondents – see example below. This ensures that the reported data remains focussed on those respondents to whom the question applied or who could recall the details. These questions are indicated using a plus (+) symbol, e.g., Q8 becomes Q8+.

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

Q8+ - WHEN YOU WERE FIRST DIAGNOSED, were you told what subtype of kidney cancer or kidney growth you had?			
Yes...	852	48%	
No...	909	52%	
<b>Total...</b>	<b>1,751</b>	<b>100%</b>	

### Data presentation

Throughout this report, percentages have been rounded to 0 decimal places. This means that sometimes the total for a single-response question can be just below or just above 100%.

### Further analysis

Significance testing and benchmarking of results have been introduced into analysis for 2022 data. More information about interpretation and presentation of this data can be found in the [detailed analysis of country data](#) and [comparisons to global findings](#) sections.

For further information on methodology, please see Appendix 2.

## USA Participant characteristics

This report outlines the results from the **115** respondents from USA. Comprised of (Q1):



74 patients

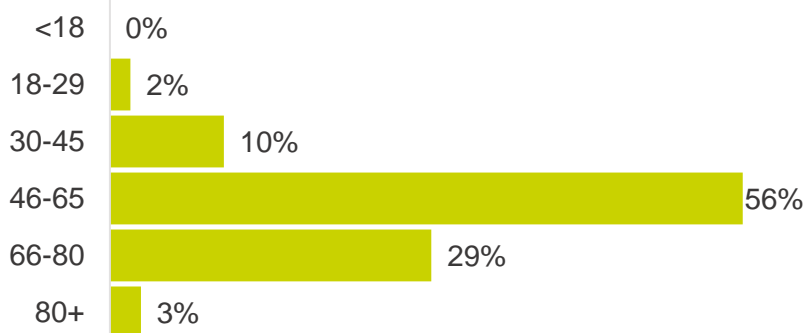


41 carers or caregivers

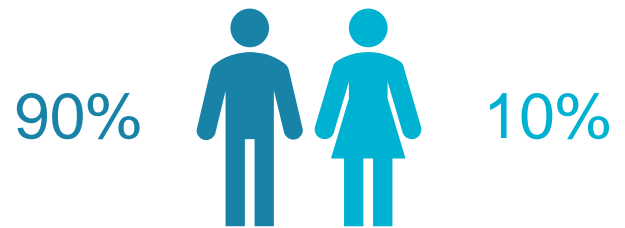


0 undisclosed

### Age (Q4/Q6, n=108)

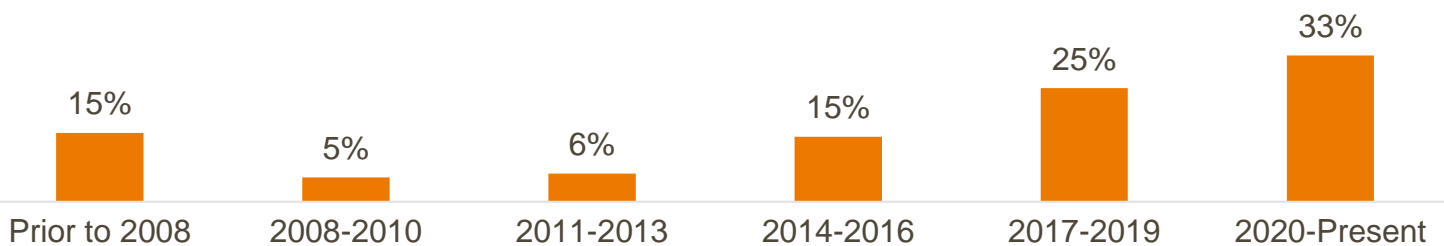


### Gender (Q5, n=115)



1% Prefer to self describe  
0% Do not wish to identify

### Year of diagnosis (Q6, n=110)



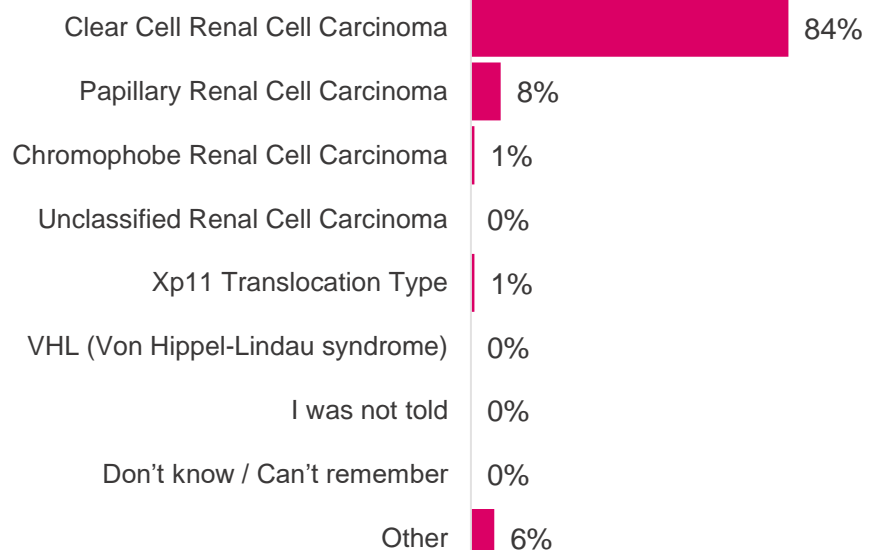
### Current stage of cancer (Q16 coded, n=97)

**Localised** 3%

**Advanced / metastatic** 64%

**No evidence / cured** 33%

### Cancer subtype (Q2, n=114)

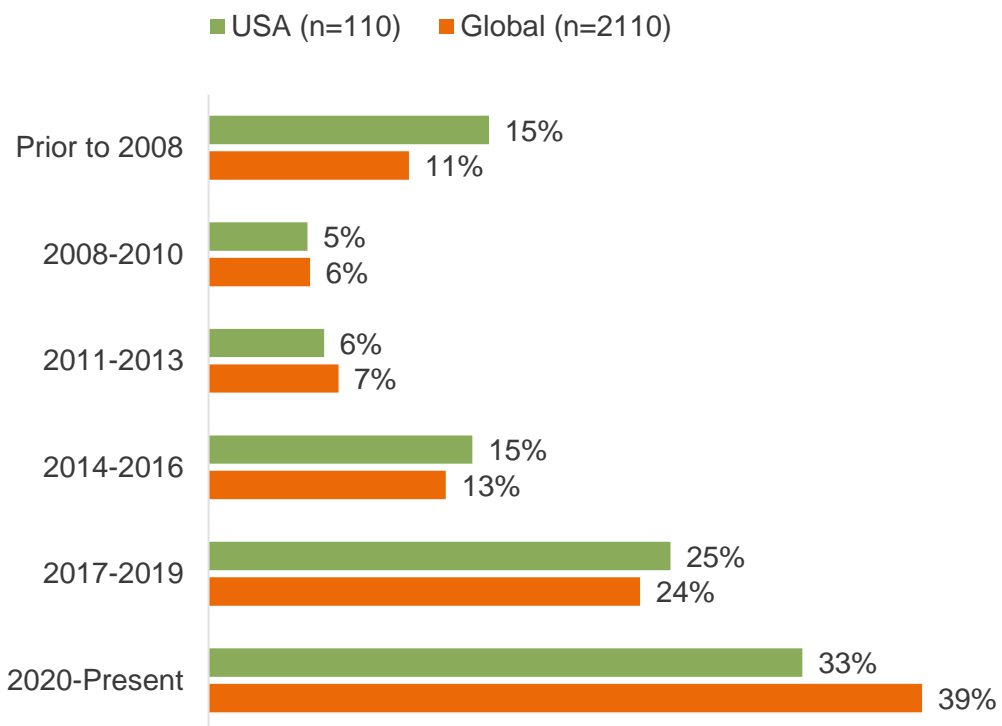


## Results: Diagnosis

The data presented in this section are from questions that asked about diagnosis.

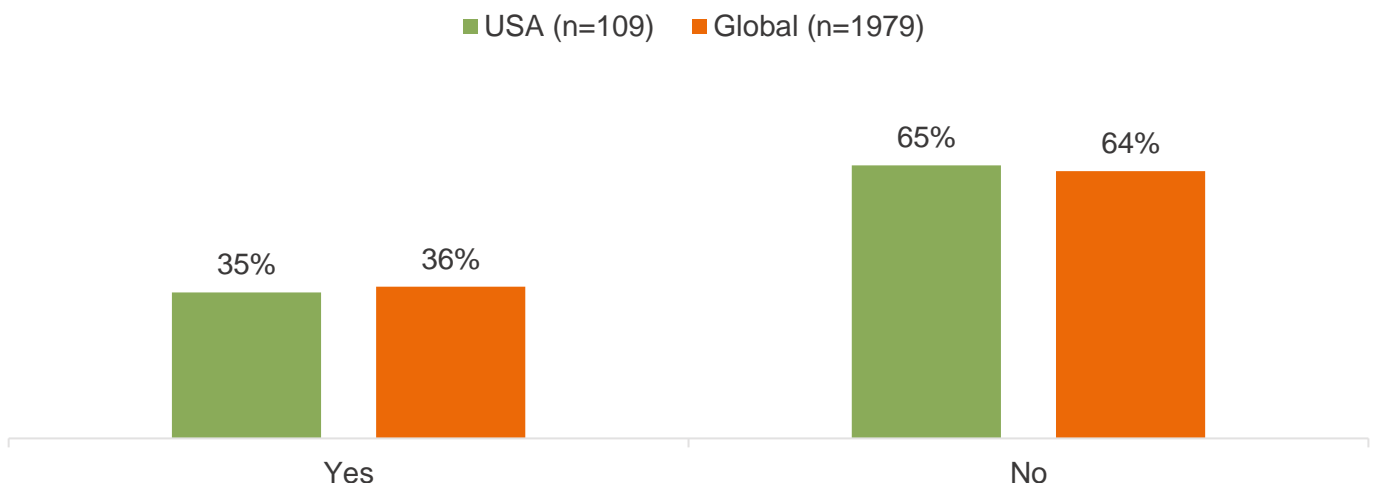
**35%** (n=38) were told what sub-type of kidney cancer or kidney growth they had when they were first diagnosed, compared to **36%** globally (n=717) (Figure 2; Q8+).

**Figure 1. Q6 - In what year were you diagnosed?**



## Subtype of kidney tumour(s) at diagnosis

**Figure 2. Q8+ - WHEN YOU WERE FIRST DIAGNOSED, were you told what sub-type of kidney cancer or kidney growth you had?**

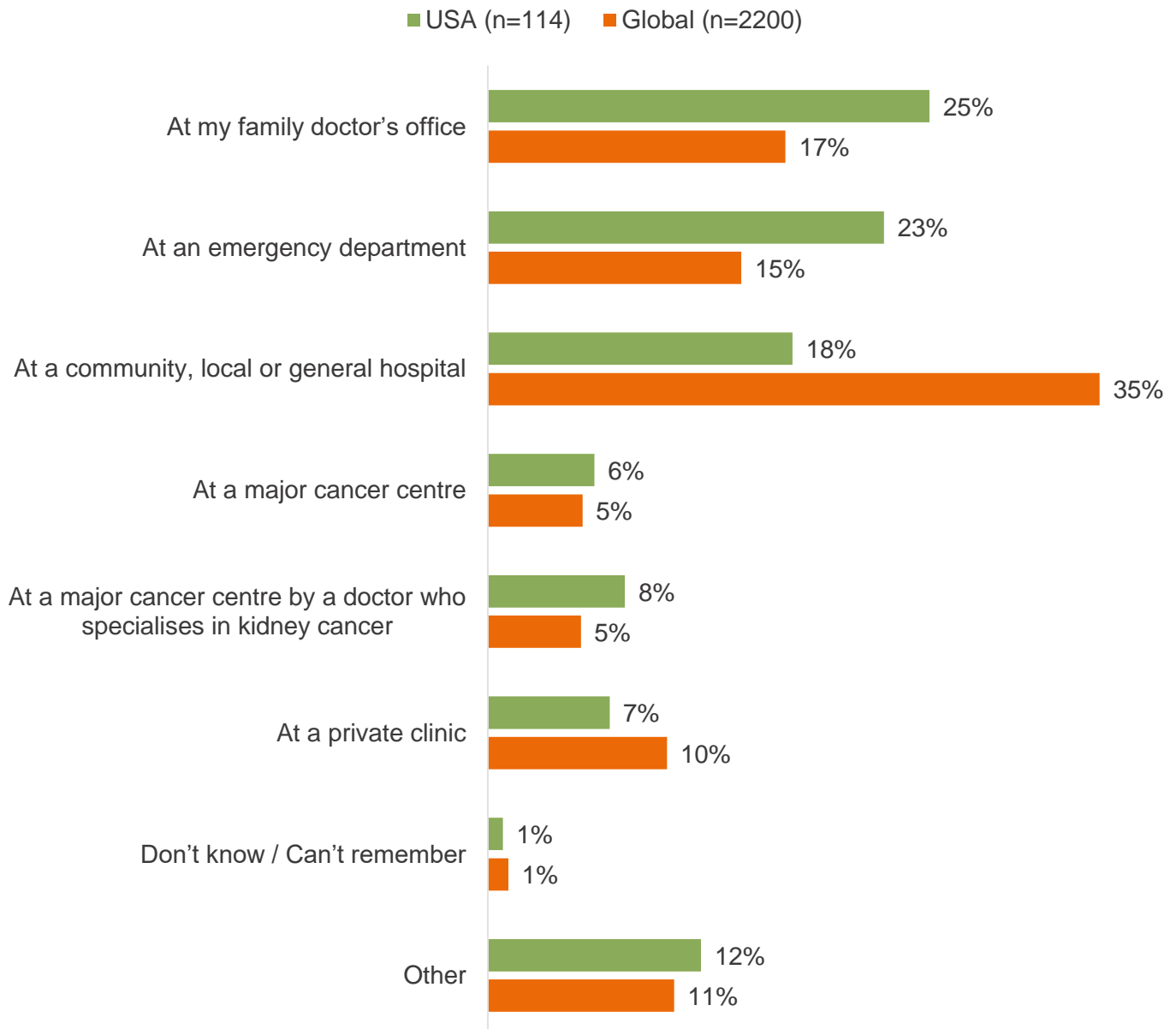


# Results: Diagnosis

Globally, respondents were most likely to be first diagnosed At a community, local or general hospital (35%, n=775) (Figure 3: Q7).

In USA, respondents were most likely to be first diagnosed At my family doctor's office (25%, n=29).

**Figure 3. Q7 - Where was your kidney cancer or kidney growth FIRST DIAGNOSED?**



# Results: Diagnosis

## Stage of kidney tumour(s) at diagnosis

At diagnosis (Figure 4: Q9):

1% (n=1) of respondents were at stage 1A

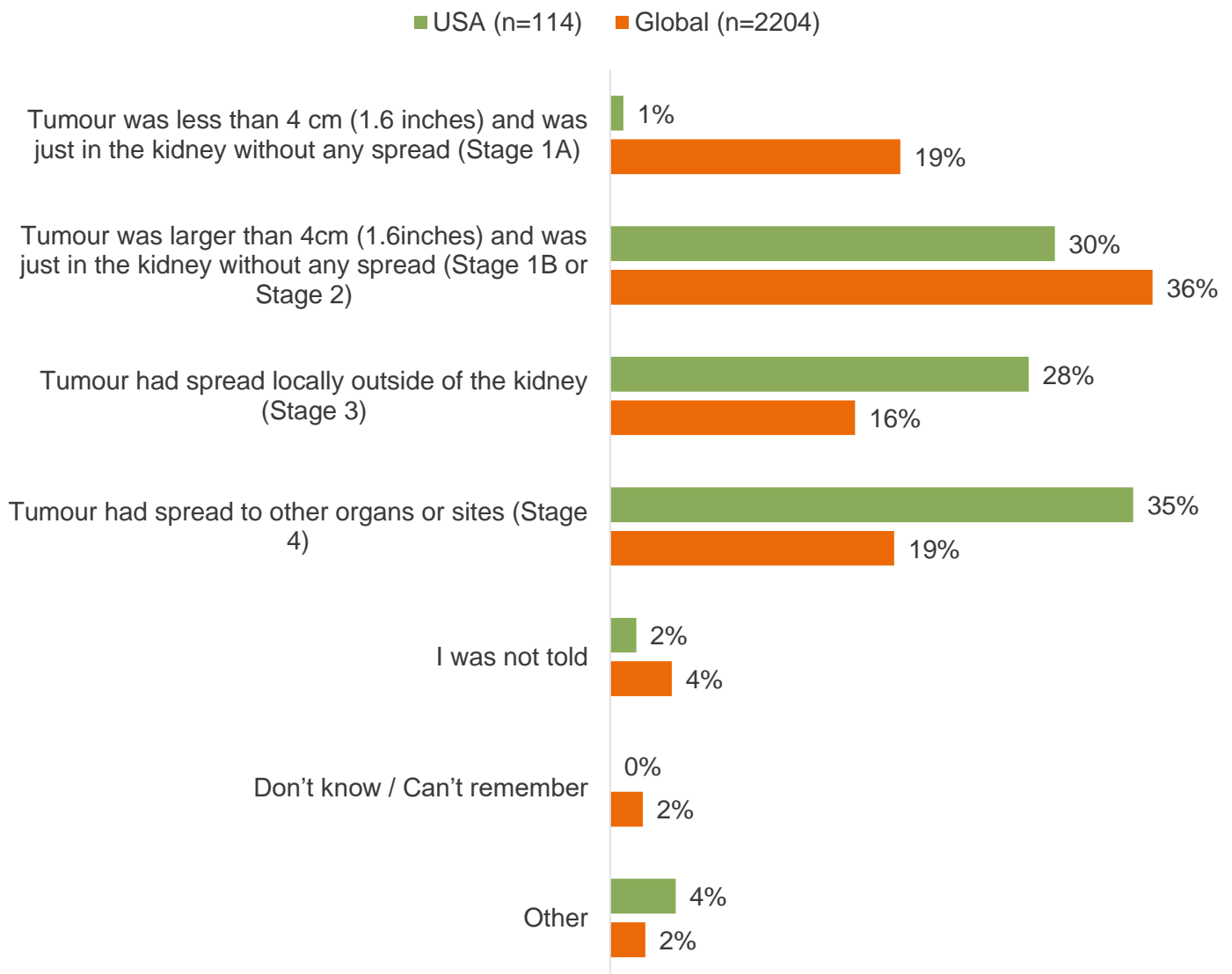
30% (n=34) were at stage 2

28% (n=32) were at stage 3

35% (n=40) were at stage 4

2% (n=2) were not told what stage their kidney tumour was at diagnosis

**Figure 4. Q9 - At what stage was the kidney tumour when you were FIRST DIAGNOSED?**

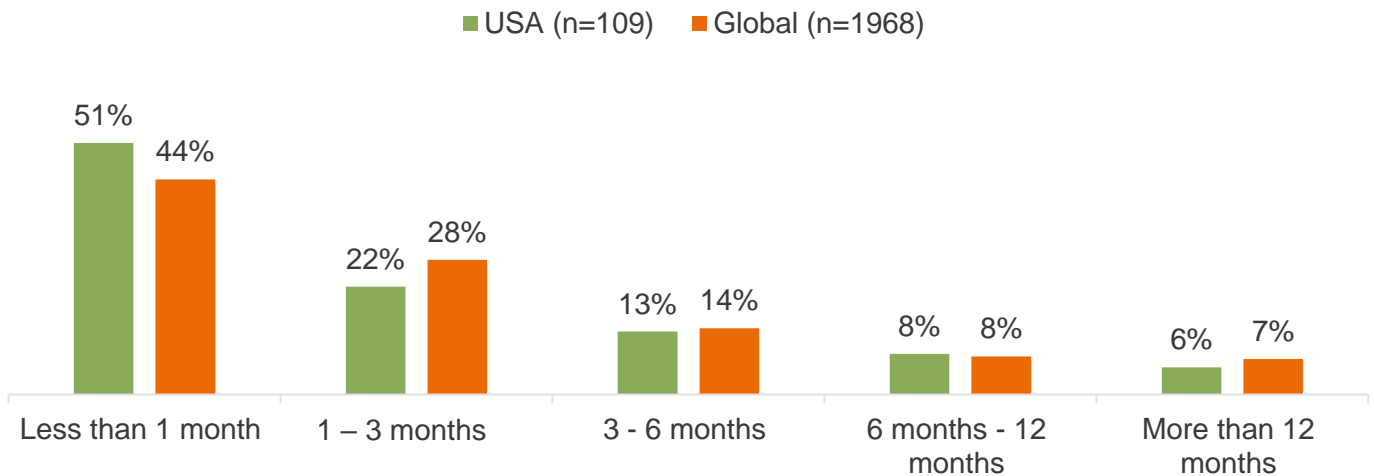


# Results: Diagnosis

## Time to correct diagnosis

**73%** of respondents (n=80) reported that it was less than 3 months between their first thinking that there might be something wrong to when they were correctly diagnosed, relative to **71%** globally (n=1407) (Figure 5; Q10+).

**Figure 5. Q10+ - How long was it from the time you first thought something might be wrong with you to being diagnosed?**

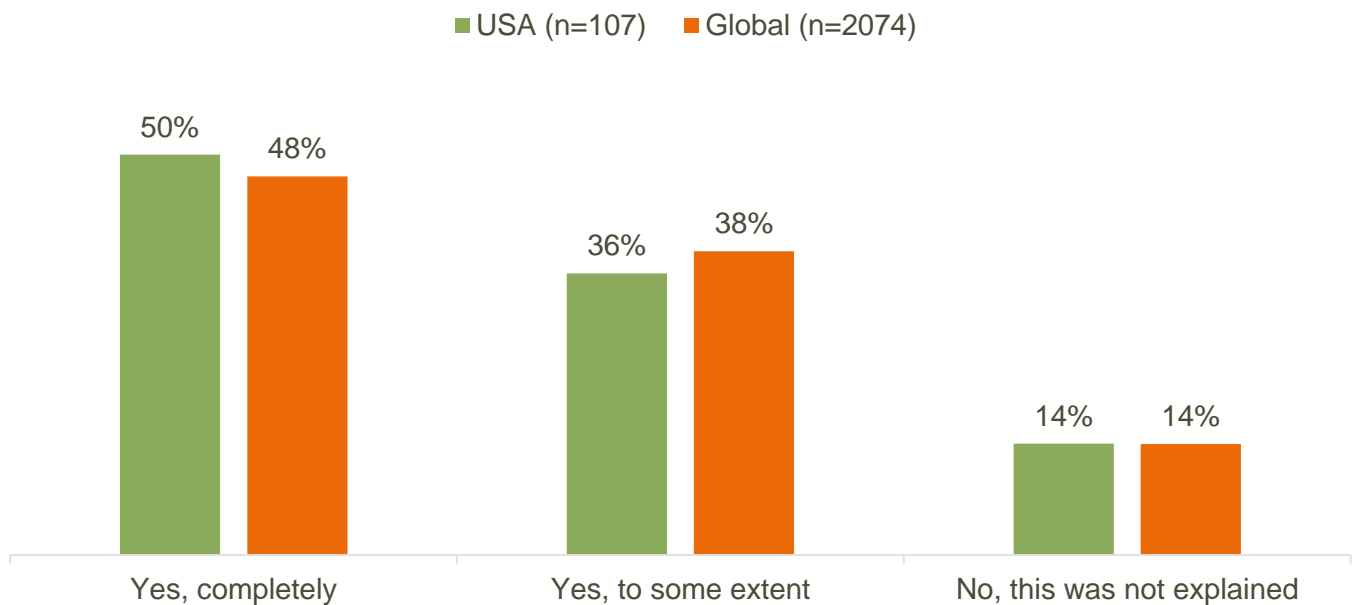


## Results: Diagnosis

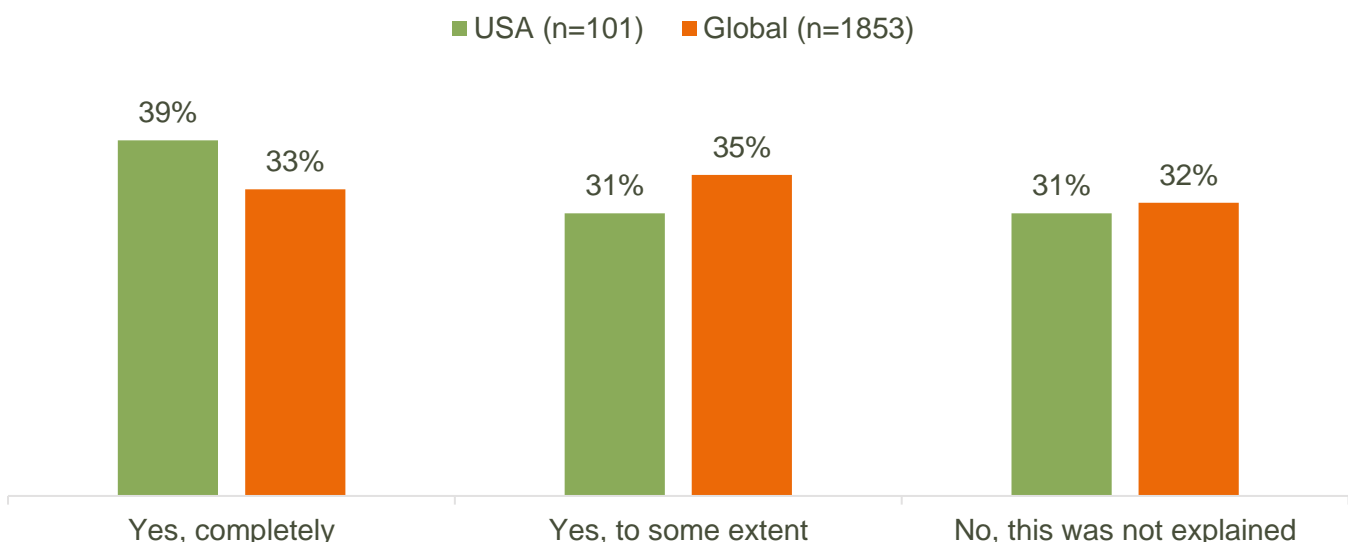
### Knowledge when planning treatments

When planning their treatments, respondents in USA were most likely to report Treatment recommendations (54%, n=58) was completely explained in a way they could understand (Figure 10; Q11\_4+). This is in contrast to Likelihood of surviving your cancer beyond five years (25%, n=26) which respondents were least likely to report as being completely explained in a way they could understand (Figure 12; Q11\_6+).

**Figure 7. Q11\_1+ – When planning your treatments, were the following explained in a way you could understand? – Stage of cancer**

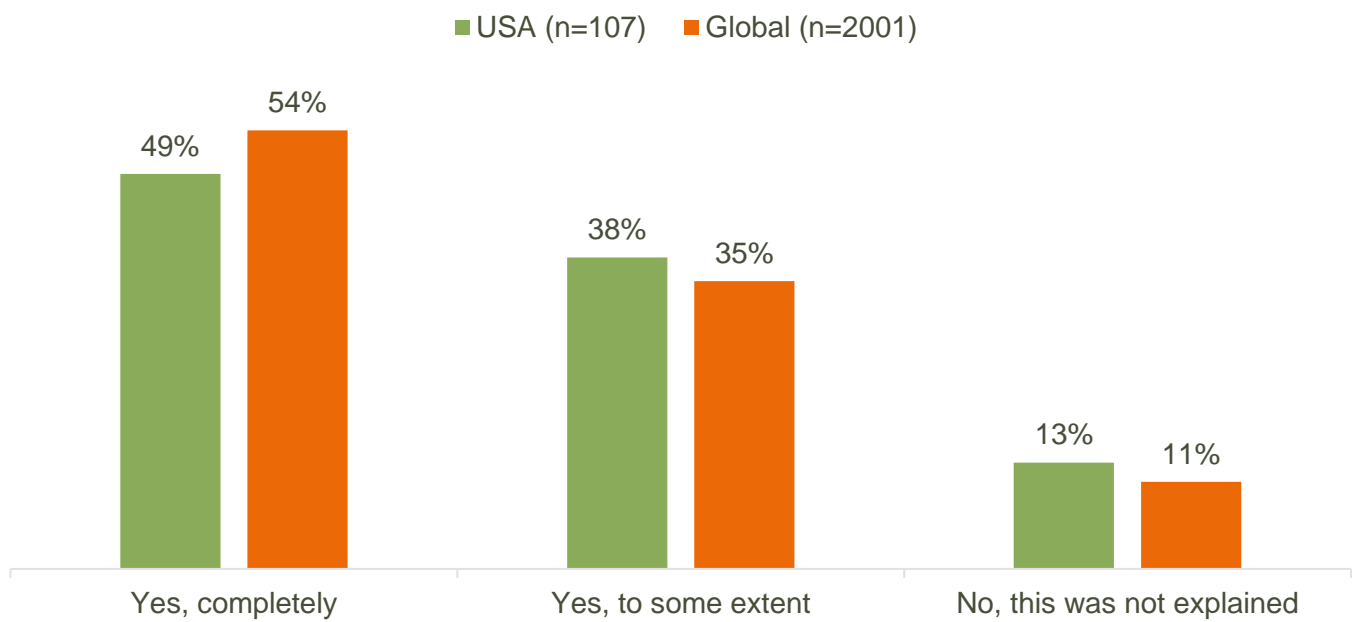


**Figure 8. Q11\_2+ – When planning your treatments, were the following explained in a way you could understand? – Sub-type of cancer**

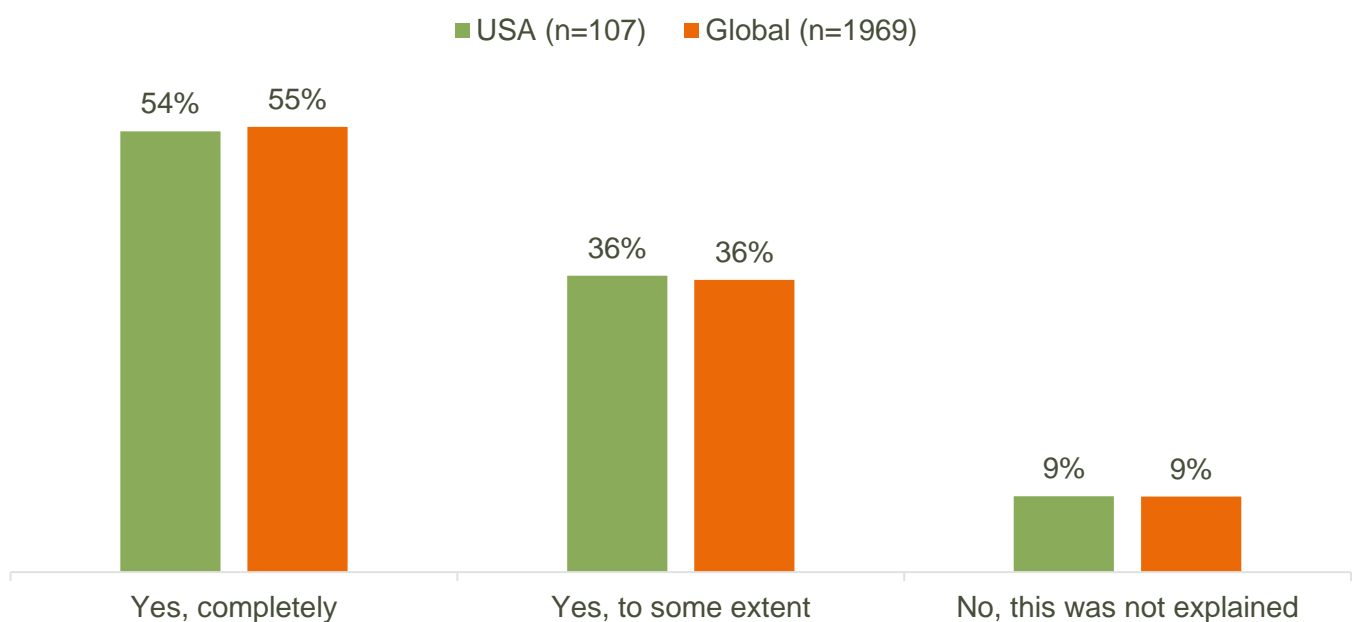


## Results: Diagnosis

**Figure 9. Q11\_3+ – When planning your treatments, were the following explained in a way you could understand? – Treatment options**



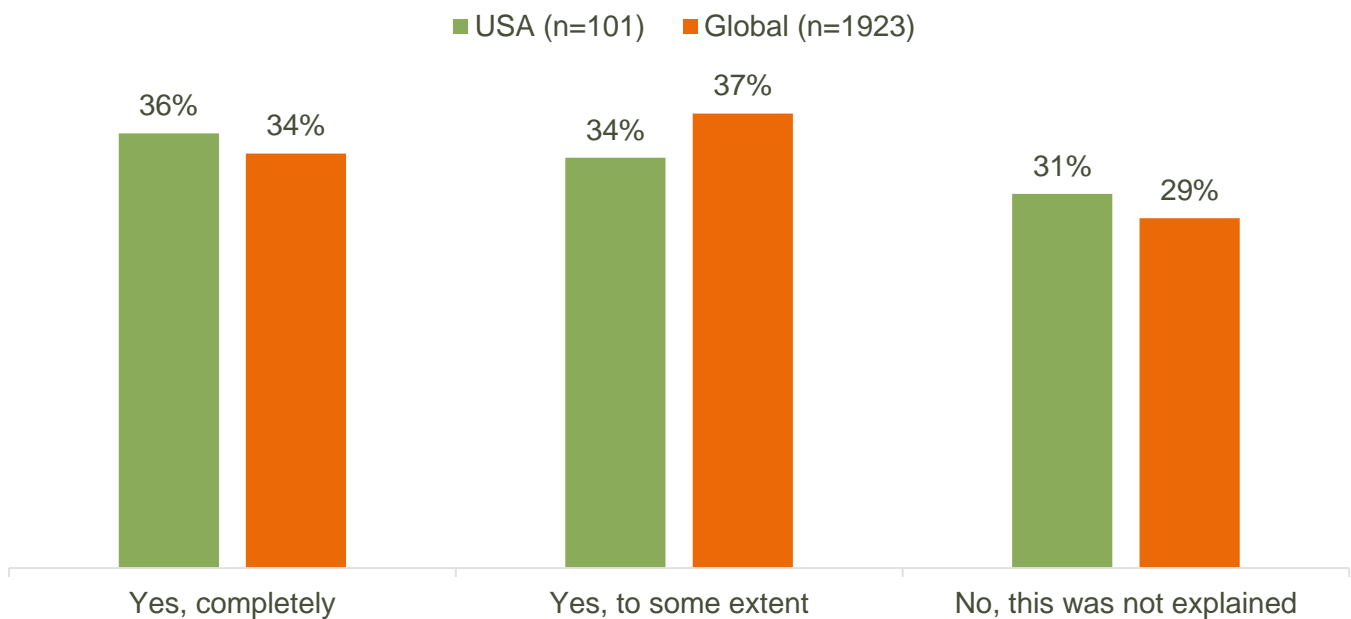
**Figure 10. Q11\_4+ – When planning your treatments, were the following explained in a way you could understand? – Treatment recommendations**



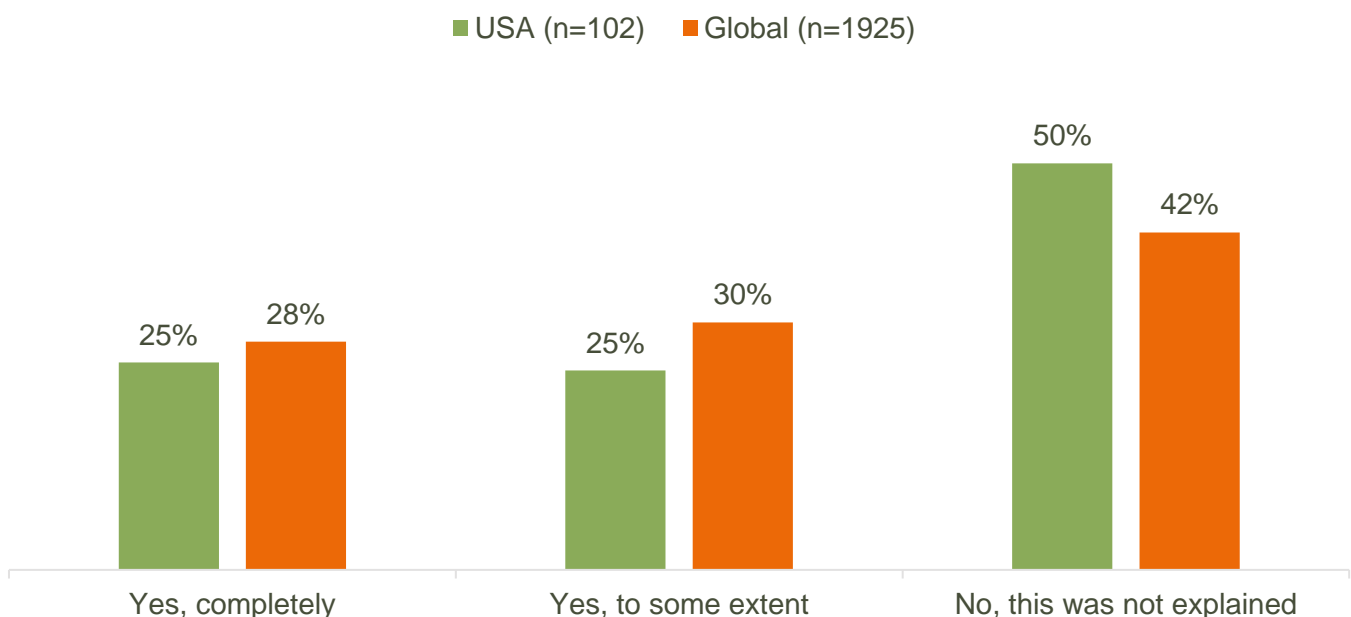


## Results: Diagnosis

**Figure 11. Q11\_5+ – When planning your treatments, were the following explained in a way you could understand? – Risk of recurrence**



**Figure 12. Q11\_6+ – When planning your treatments, were the following explained in a way you could understand? – Likelihood of surviving your cancer beyond five years**

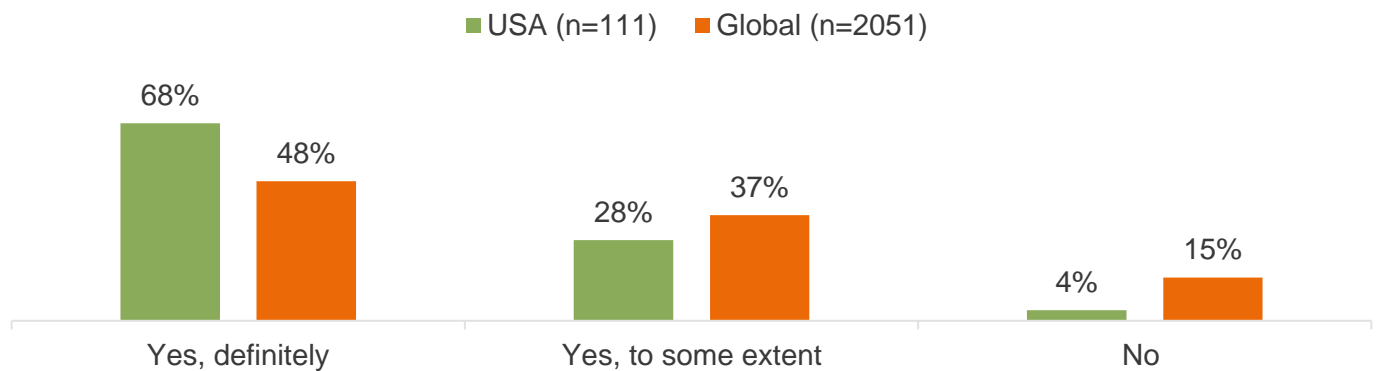


## Results: Developing a treatment plan/ shared decision making

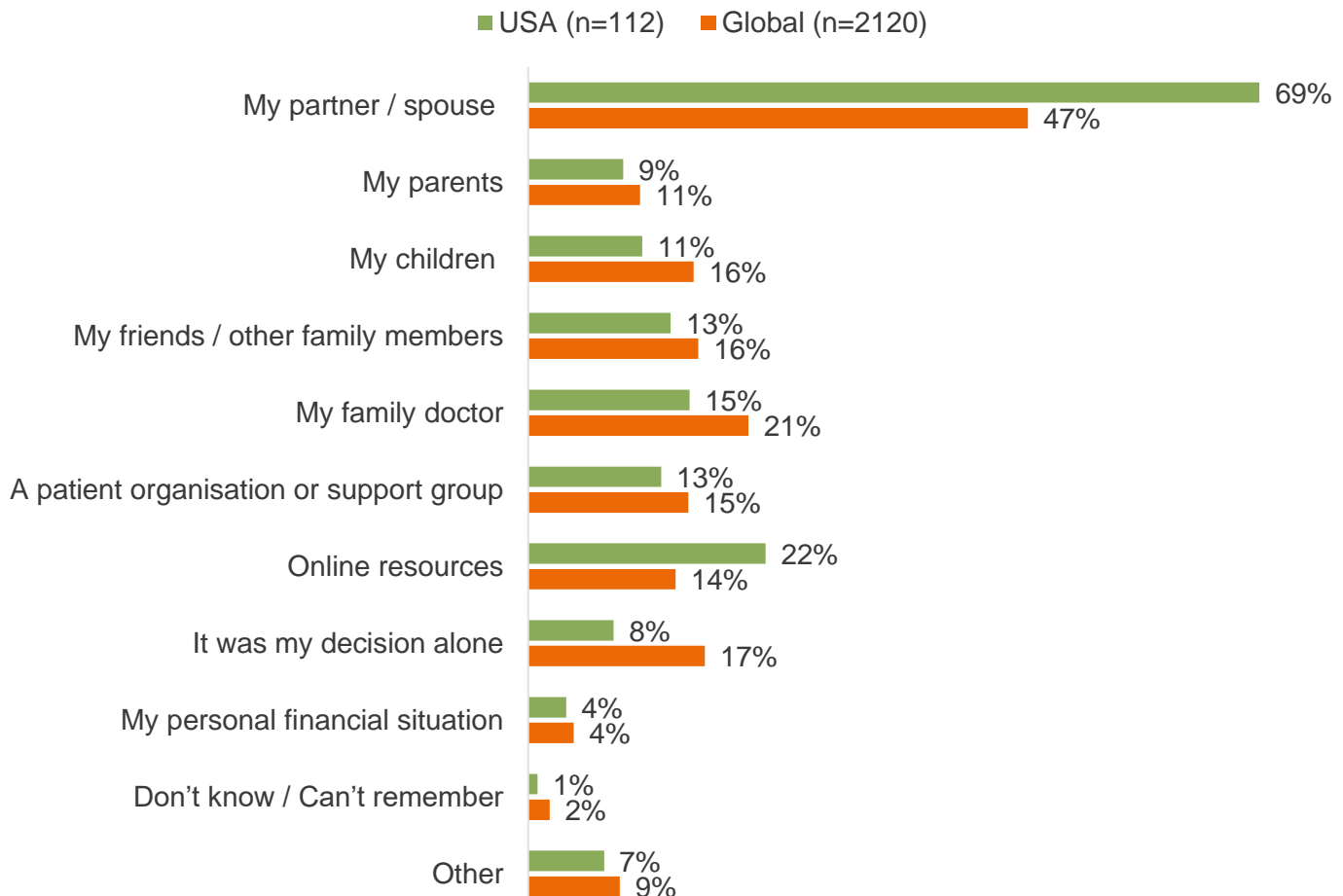
The data presented in this section are from questions that asked about developing a treatment plan and shared decision making.

68% of respondents (n=76) reported that they were definitely involved as much as they wanted to be in developing their treatment plan, compared to 48% globally (n=992) (Figure 13; Q13+).

**Figure 13. Q13+ - Were you involved as much as you wanted to be in decisions about your treatment plan?**



**Figure 14. Q14 - Who or what else helped you make decisions about your treatment plan? [multiple choice]**



# Results: Kidney Cancer care and treatment

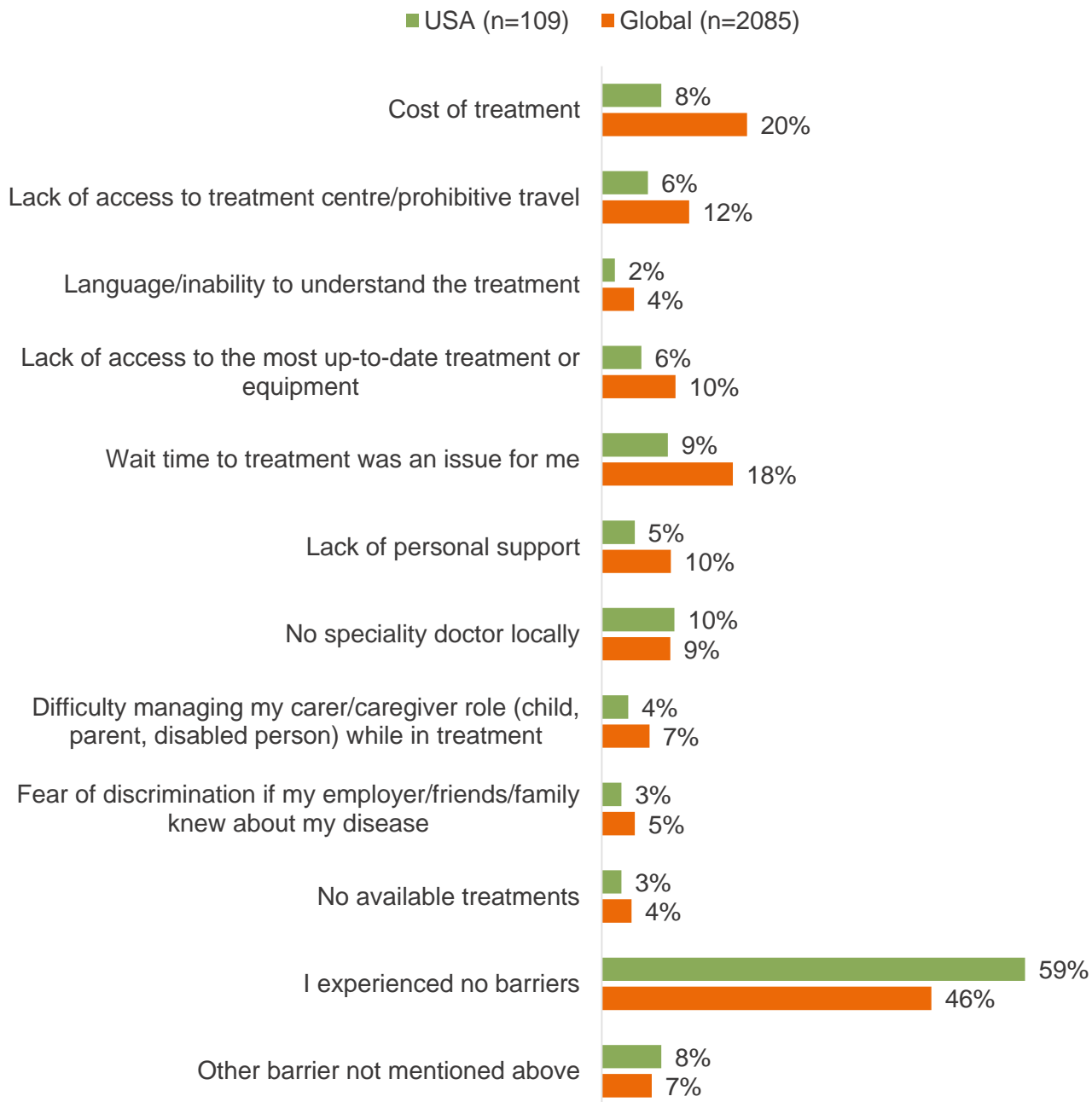
## Barriers to treatment

The data presented in this section are from questions that asked about care and treatment.

**59%** of respondents (n=64) reported experiencing no barriers to treatment, relative to **46%** globally (n=953) (Figure 15; Q15).

The most commonly experienced barrier to treatment reported in USA was No speciality doctor locally (**10%**, n=11).

**Figure 15. Q15 - Which barriers (if any) have you experienced that affected your treatment choices for your kidney cancer or kidney growth? [multiple choice]**



## Results: Kidney Cancer care and treatment

### Getting a second opinion

Respondents were asked whether they ever sought a second opinion about their kidney cancer (Figure 16: Q12).  
In USA:

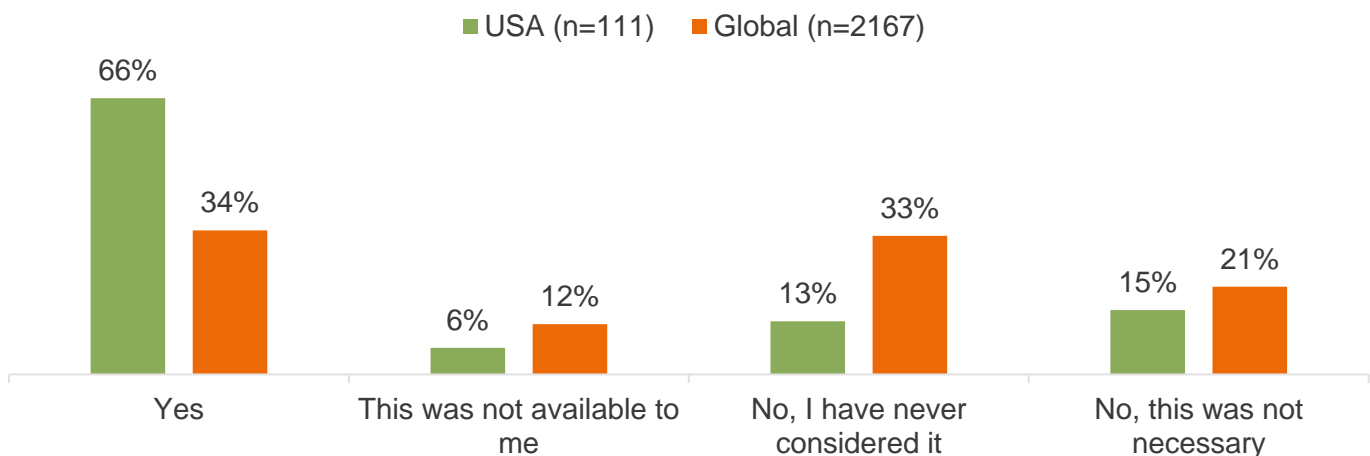
**66%** (n=73) did seek a second opinion

**6%** (n=7) reported this was not available to them

**13%** (n=14) stated they had never considered seeking a second opinion

**15%** (n=17) said seeking a second opinion was not necessary

**Figure 16. Q12 - Did you ever seek a second opinion about your kidney cancer?**



## Results: Care and treatment today

The data presented in this section are from questions that asked about care today (at time of survey completion).

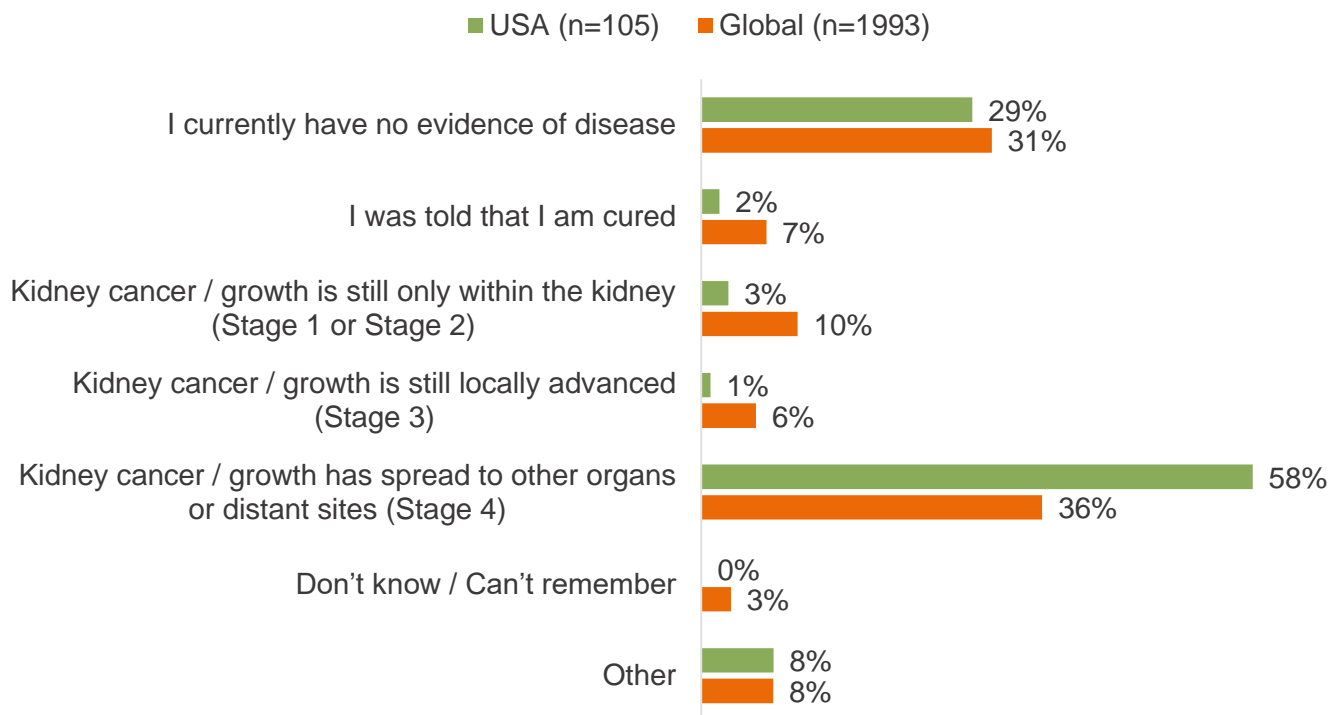
At the time of completing the survey (Figure 17; Q16):

**30%** (n=32) had no evidence of disease / were cured

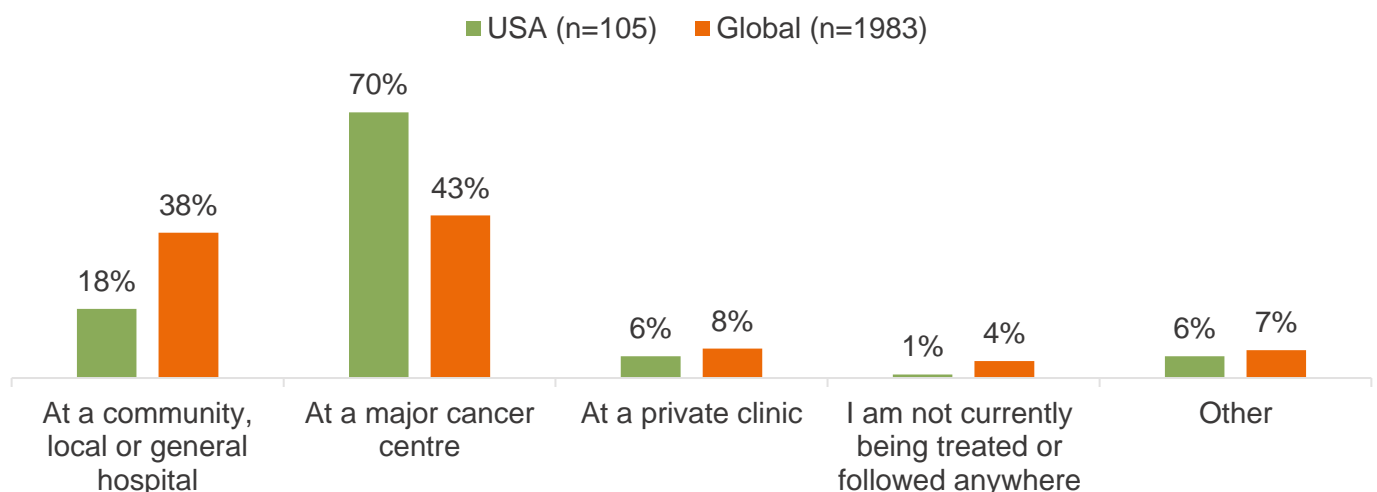
**3%** (n=3) reported their kidney cancer / tumour remained localised (Stage 1 or 2)

**59%** (n=62) reported their kidney cancer / tumour was advanced / metastasised (Stage 3 or 4)

**Figure 17. Q16 - Which of the following best describes your stage of kidney cancer or kidney growth TODAY?**



**Figure 18. Q17 - Where are you CURRENTLY being treated or followed?**



## Results: Care and treatment today

### Understanding of medical care and treatment

The survey asked respondents to consider their level of understanding of their care and treatment at the time of completing the survey (Q18+, Q19+):

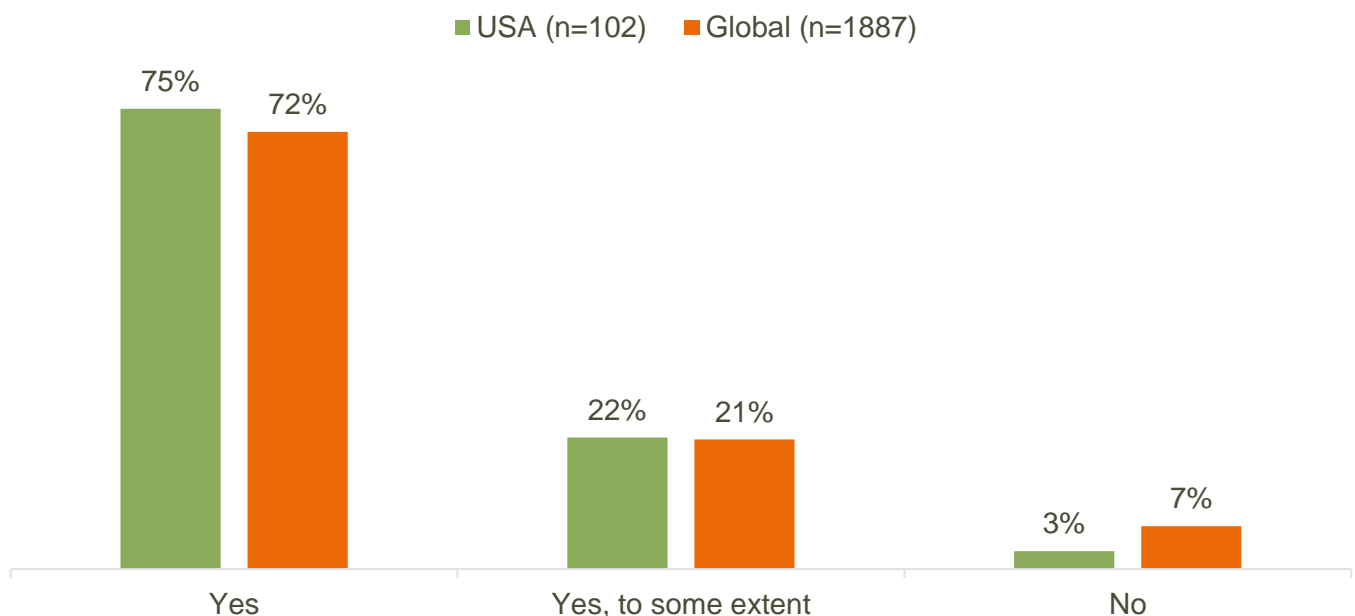
In USA, respondents were most likely to completely understand:

- The importance of lifestyle choices for my wellbeing (e.g. avoiding smoking, being active) (**80%**, n=84) (Figure 28; Q19\_3+)
- Surgical options (**75%**, n=77) (Figure 19; Q18\_1+)
- Immunotherapy options (**73%**, n=74) (Figure 20; Q18\_2+)

In contrast, USA respondents were least likely to completely understand:

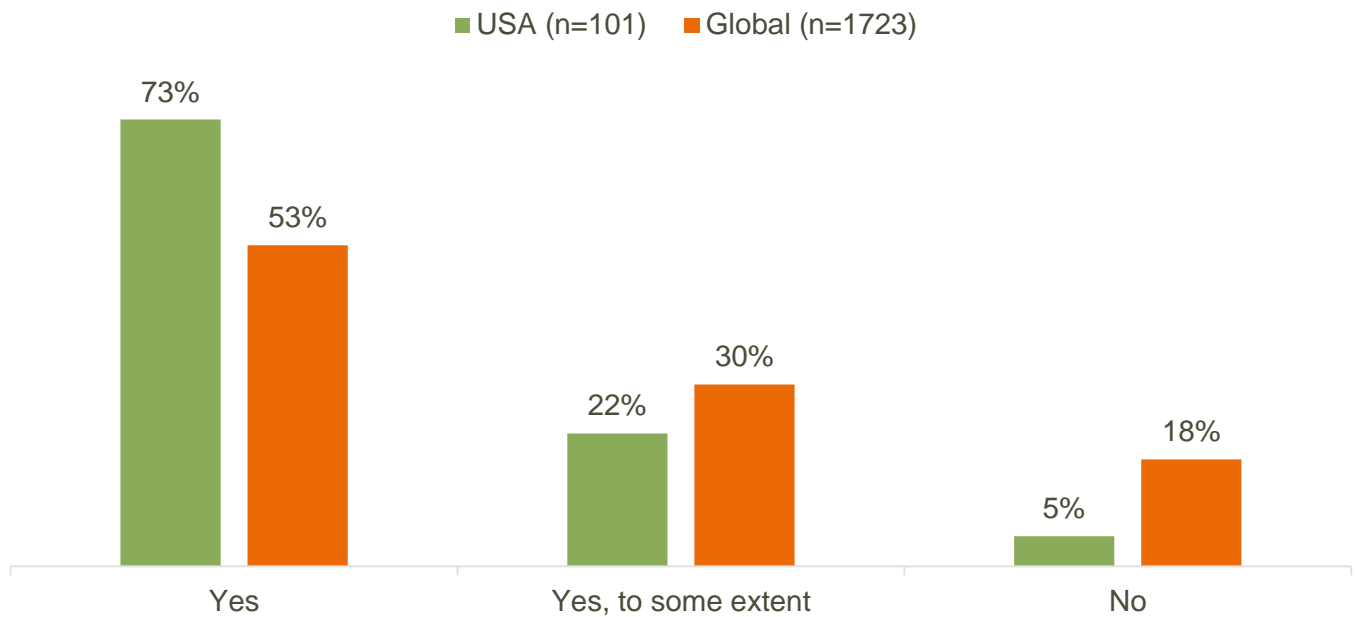
- Ablative therapy options (cryoablation or radiofrequency ablation) (**32%**, n=31) (Figure 23; Q18\_5+)
- Complementary therapies (e.g. meditation, etc.) (**37%**, n=37) (Figure 29; Q19\_4+)
- Adjuvant therapy (treatment aimed at reducing the chance of recurrence after surgery) (**42%**, n=35) (Figure 25; Q18\_7+)

**Figure 19. Q18\_1+ - Do you understand the following? – Surgical options**

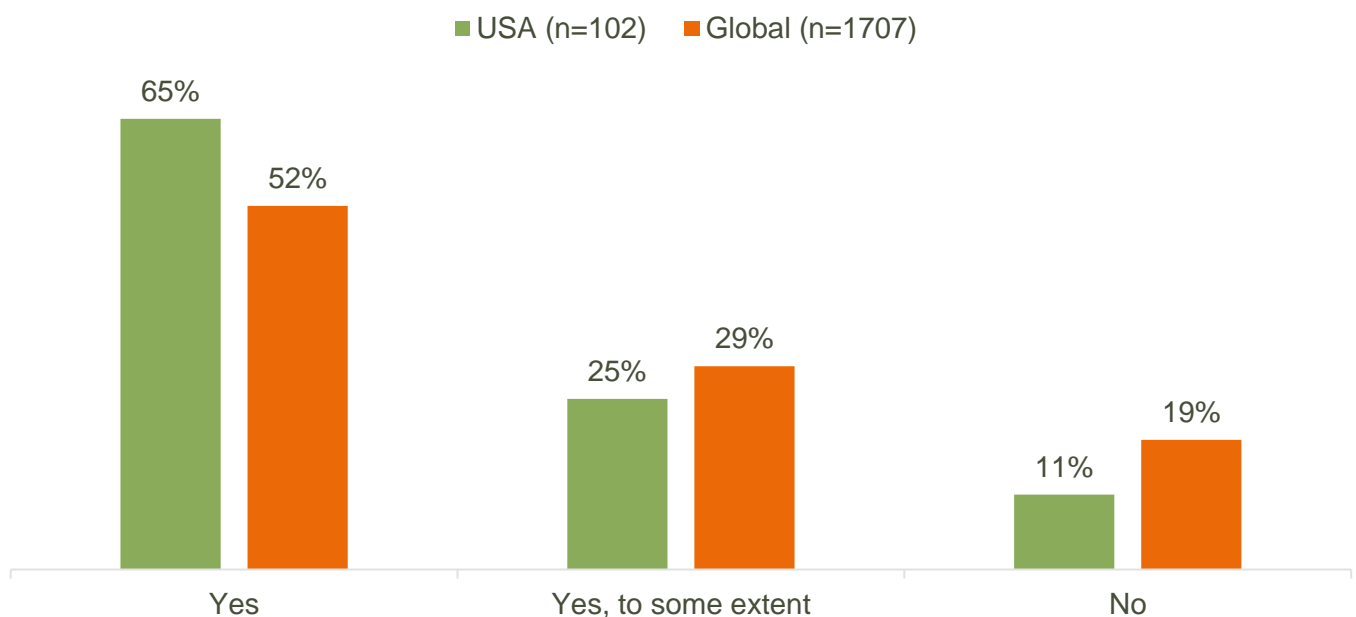


## Results: Care and treatment today

**Figure 20. Q18\_2+ – Do you understand the following? – Immunotherapy options**

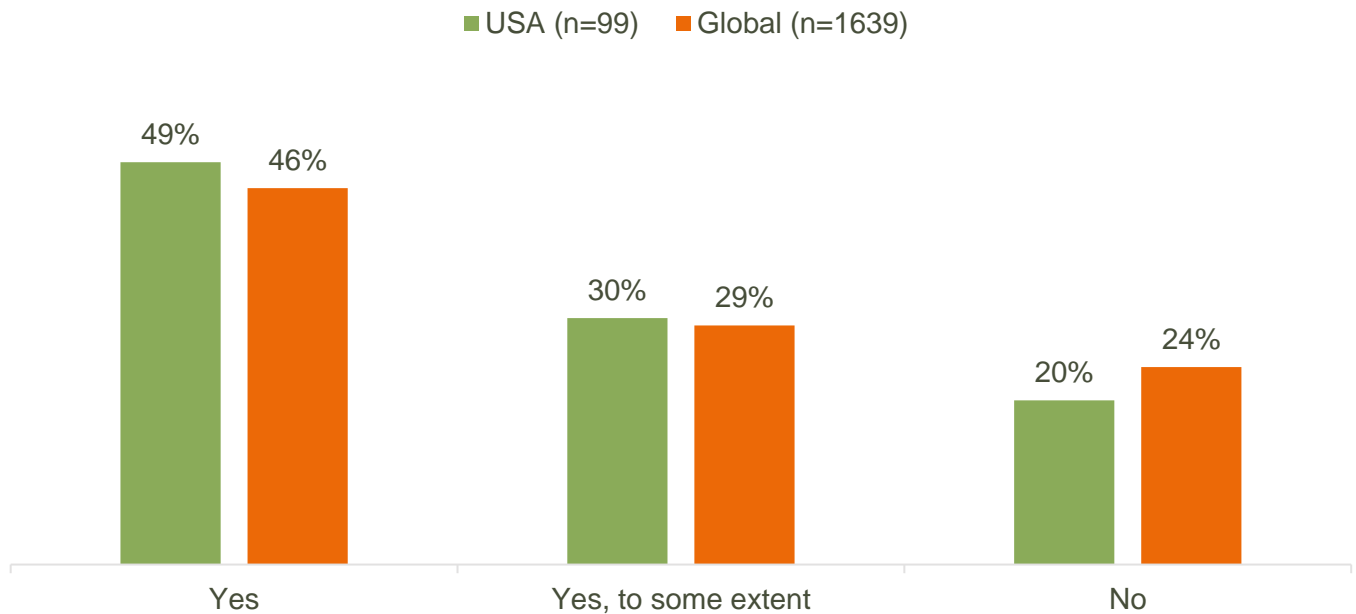


**Figure 21. Q18\_3+ - Do you understand the following? - Targeted therapy options (pills or tablets)**

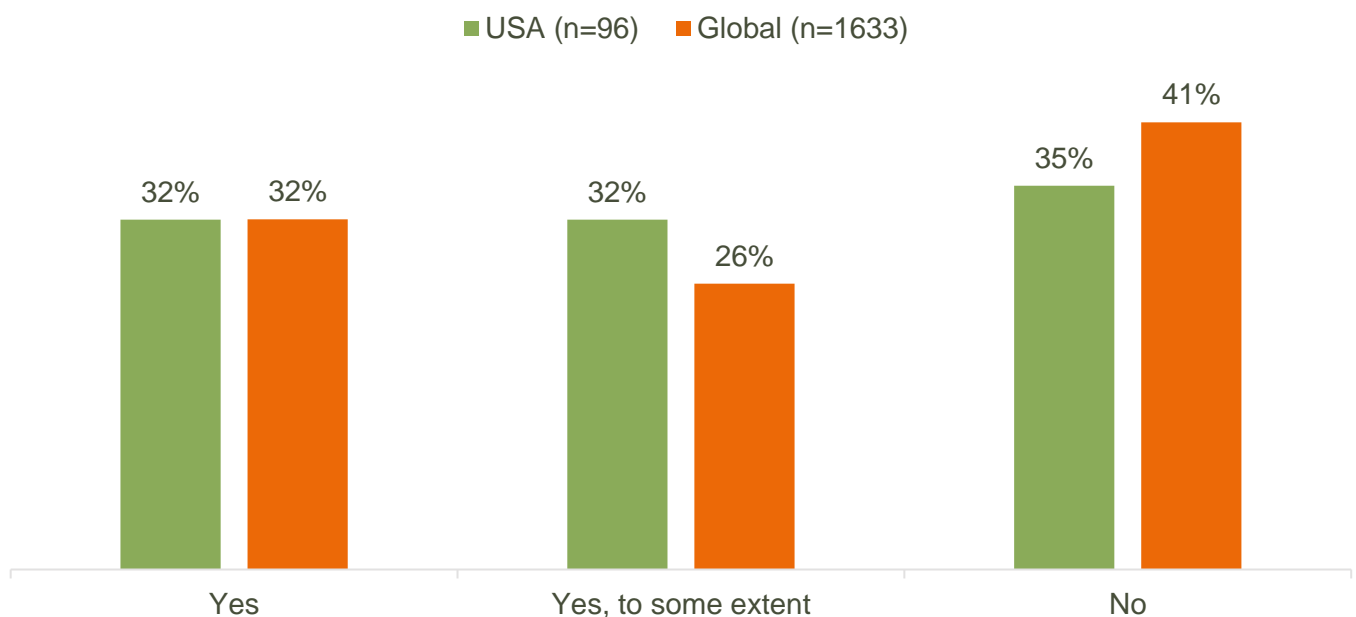


## Results: Care and treatment today

**Figure 22. Q18\_4+ – Do you understand the following? – Radiation therapy options**



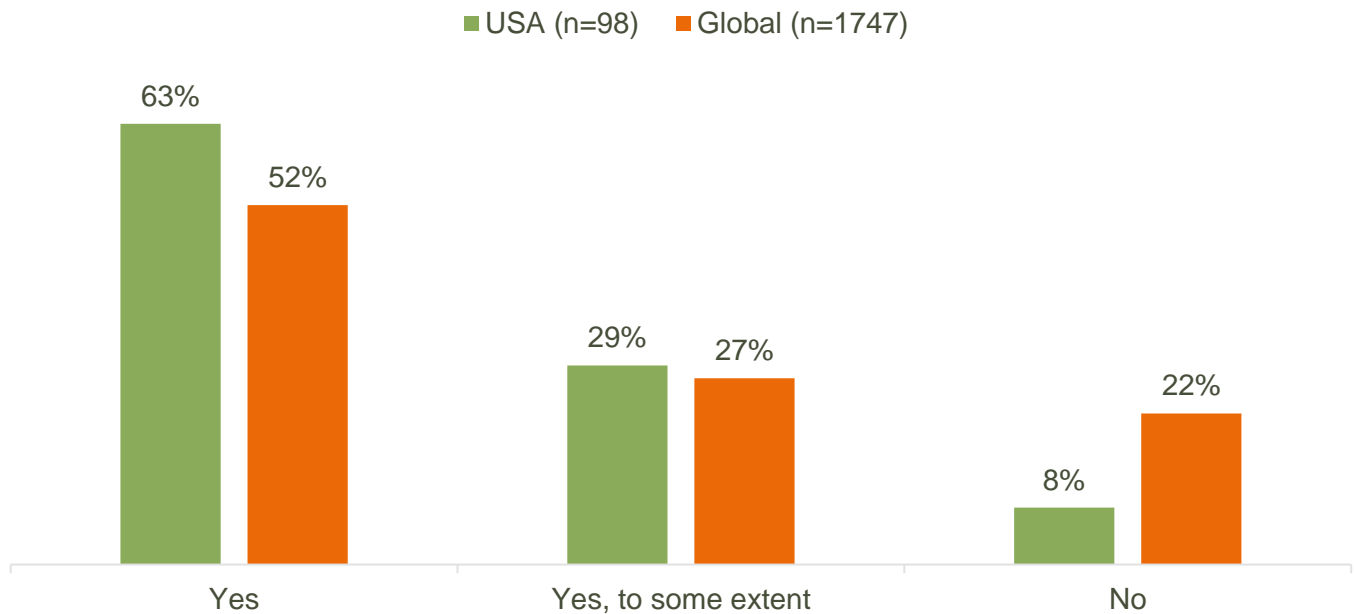
**Figure 23. Q18\_5+ - Do you understand the following? - Ablative therapy options (cryoablation or radiofrequency ablation)**



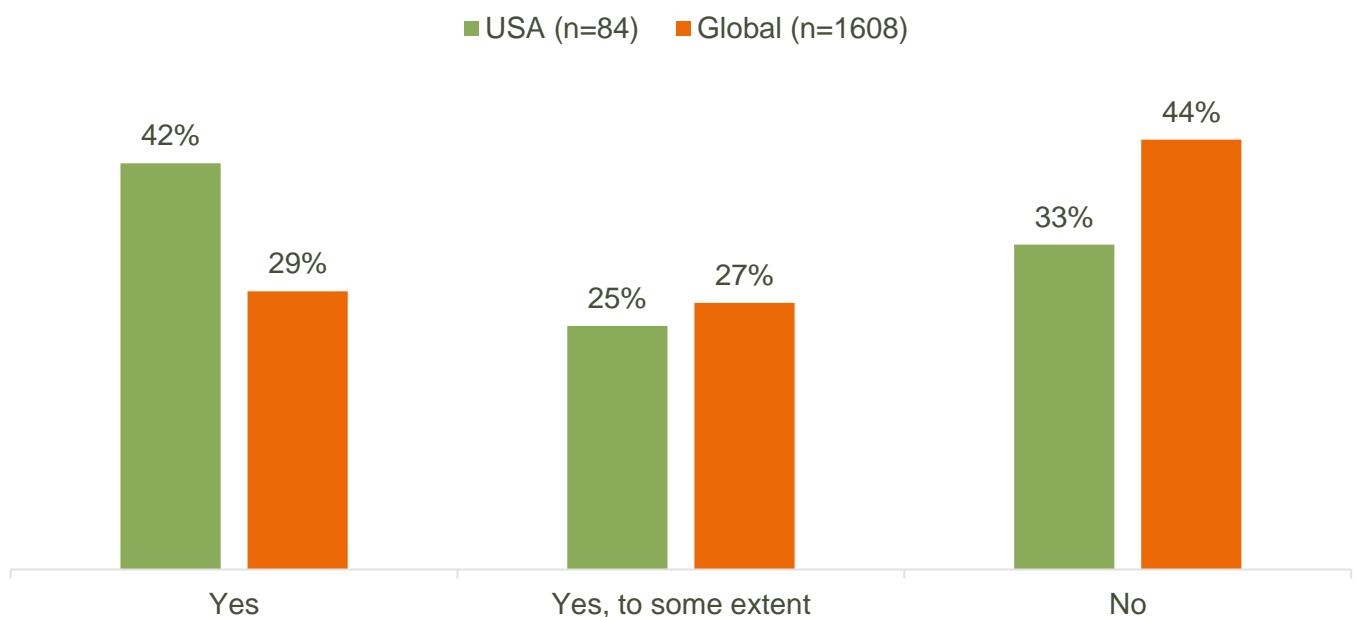


## Results: Care and treatment today

**Figure 24. Q18\_6+ – Do you understand the following? – Active surveillance**



**Figure 25. Q18\_7+ - Do you understand the following? - Adjuvant therapy (treatment aimed at reducing the chance of recurrence after surgery)**



## Results: Care and treatment today

### Understanding of supportive care

Figure 26. Q19\_1+ – Do you understand the following? – Palliative/ supportive care

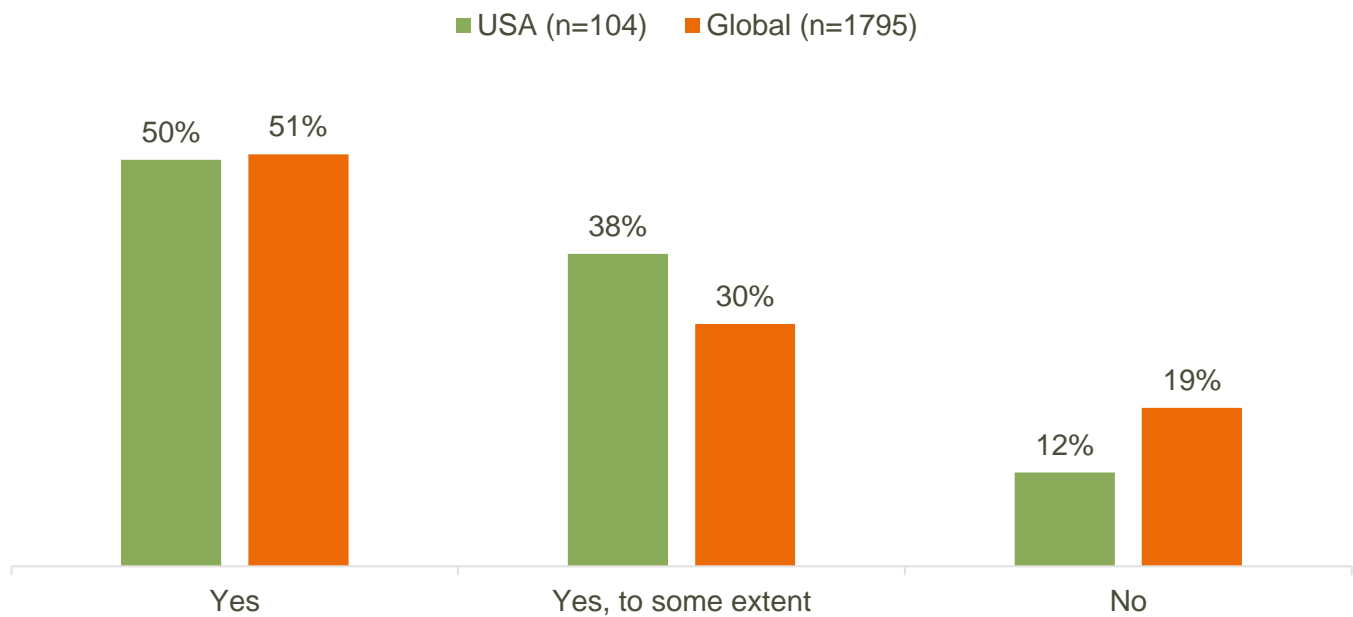
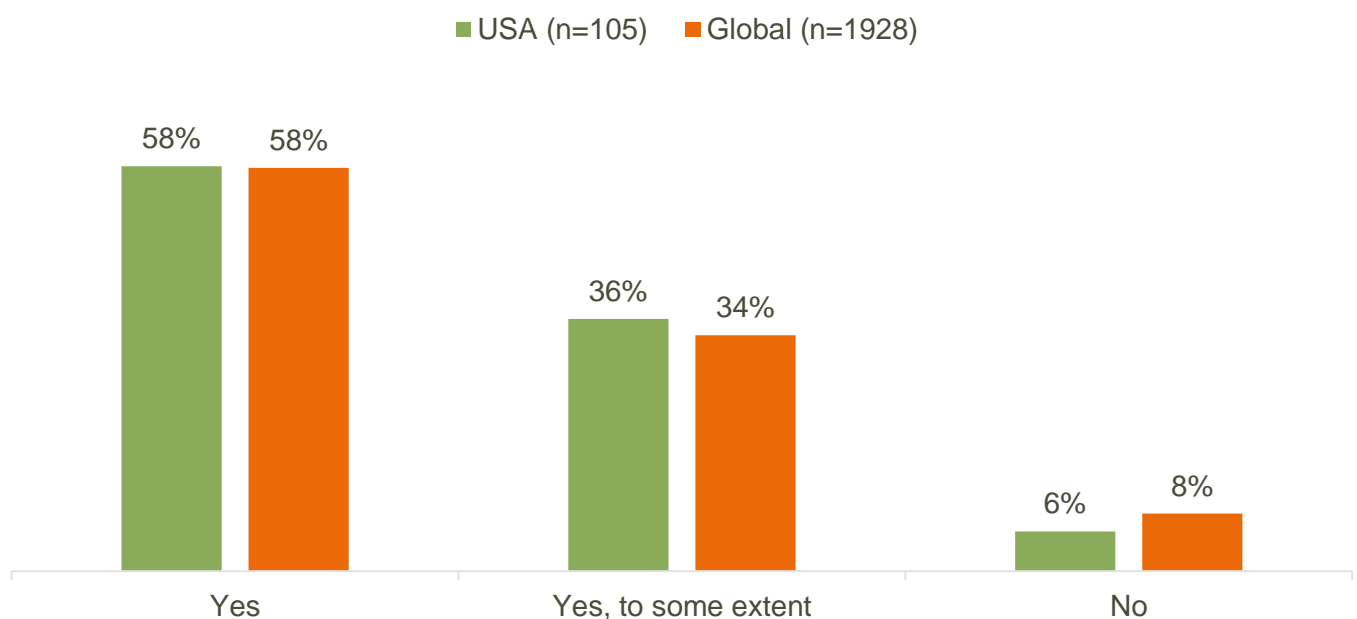
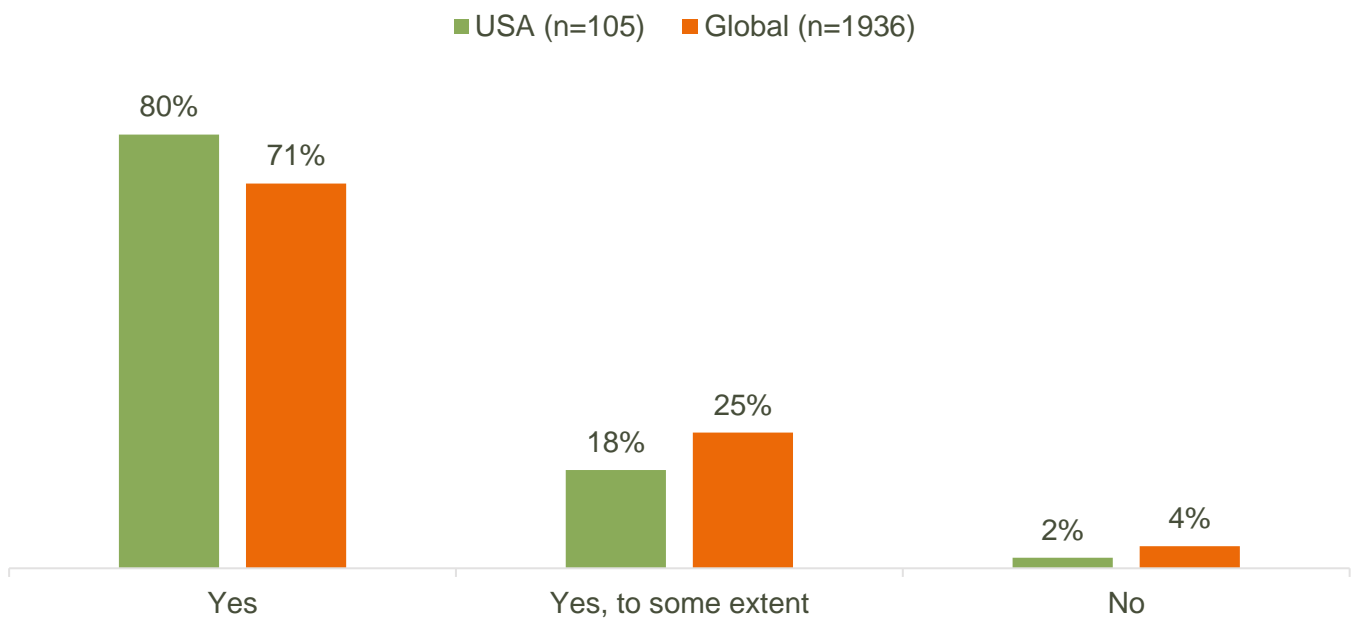


Figure 27. Q19\_2+ - Do you understand the following? - The importance of good nutrition for my well-being

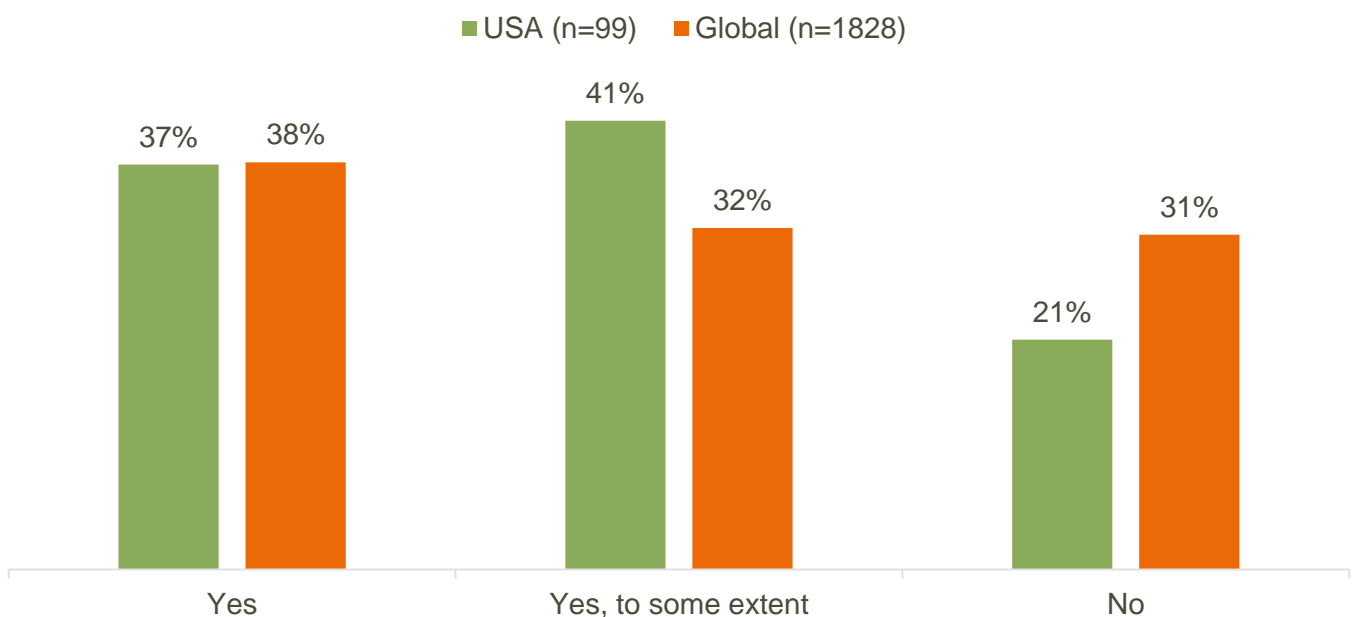


## Results: Care and treatment today

**Figure 28. Q19\_3+ – Do you understand the following? – The importance of lifestyle choices for my wellbeing (e.g. avoiding smoking, being active)**

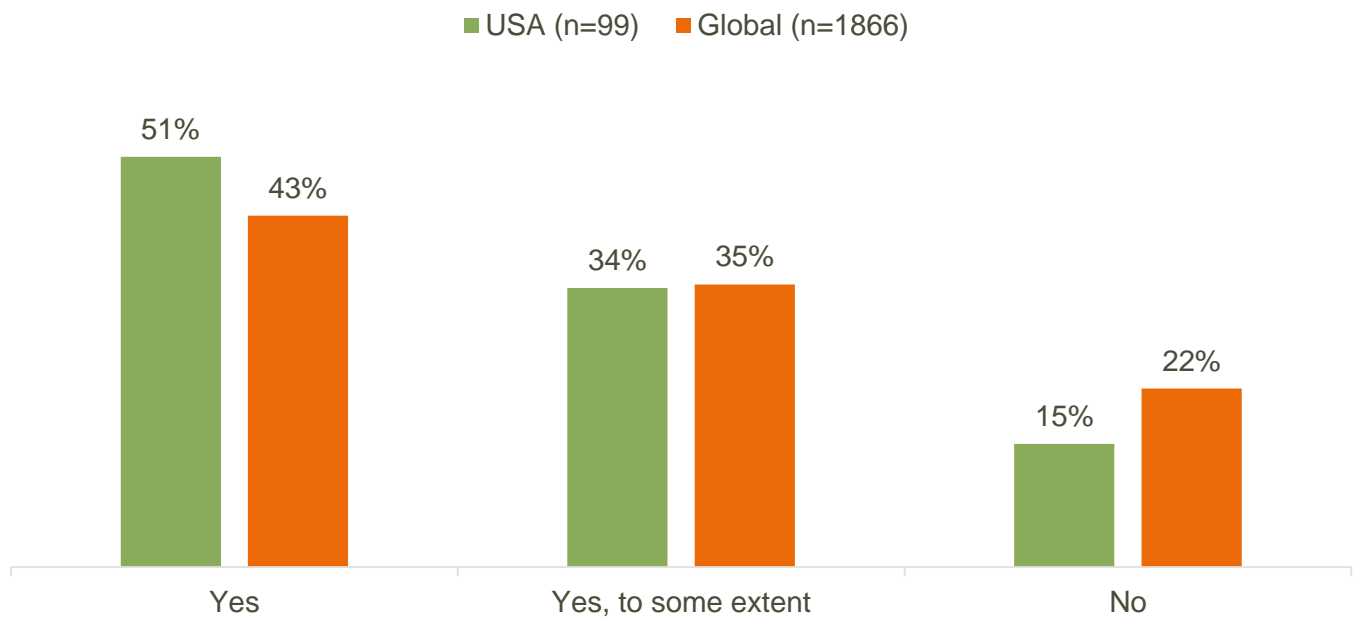


**Figure 29. Q19\_4+ - Do you understand the following? - Complementary therapies (e.g. meditation, etc.)**



## Results: Care and treatment today

Figure 30. Q19\_5+ – Do you understand the following? – My local guidelines for kidney cancer care and follow up



# Results: Biopsy and active surveillance for small renal mass

## Management of small renal masses

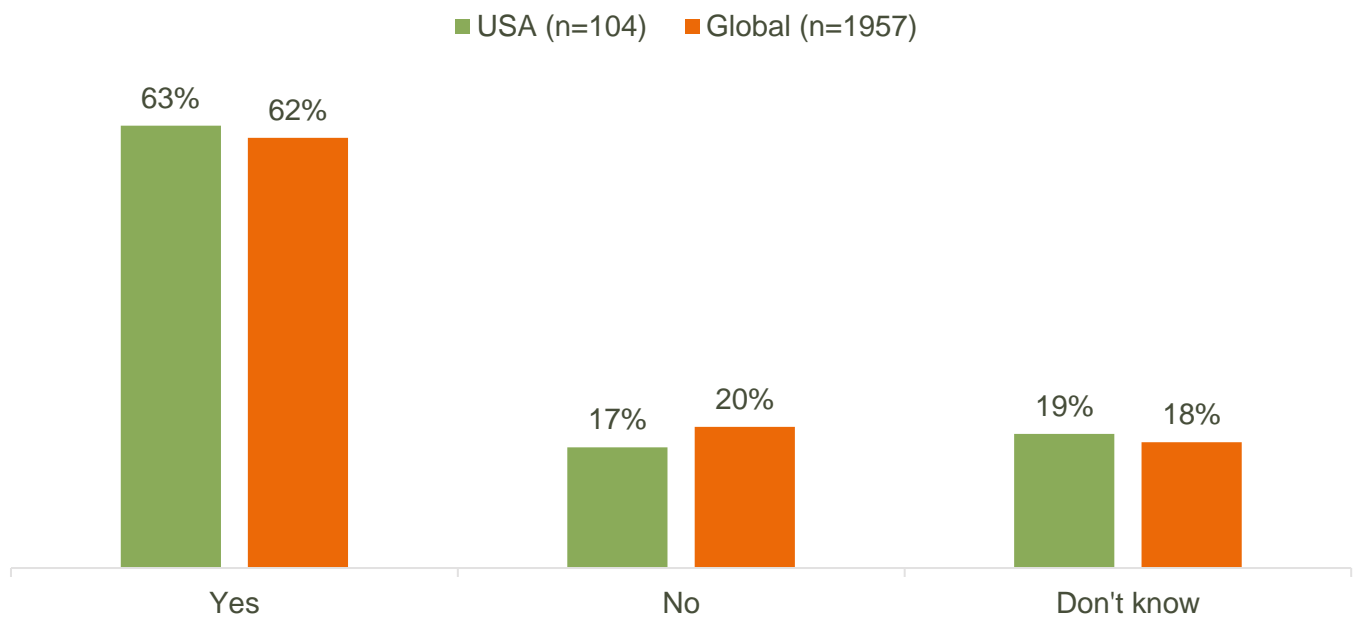
Respondents were asked about their willingness to participate in biopsy and active surveillance. Of USA respondents:

**63%** (n=66) reported that they would be willing to participate in active surveillance with regular imaging such as ultrasound and CT if their doctor recommended this (Figure 31; Q20).

**82%** (n=85) would be willing to have a biopsy of the small renal growth if it might change the treatment decision (Figure 32; Q21) .

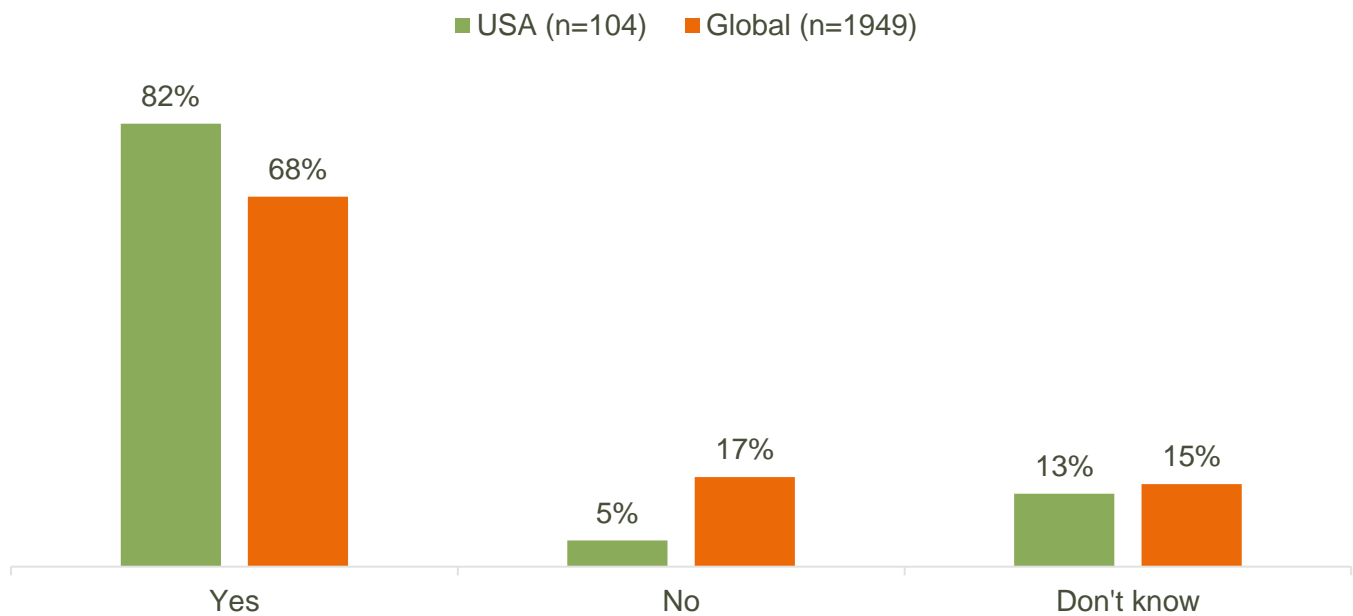
Respondents were then asked how long they would prefer to have regular imaging scans (ultrasound or CT) for surveillance following surgery for their kidney cancer or kidney growth (Figure 33; Q22). In USA, respondents were most likely to prefer this form of surveillance for I would decide based on my healthcare team’s opinion (**30%**, n=31). Globally, respondents preferred length of surveillance was less than 2 years (**32%**, n=638).

**Figure 31. Q20 - When a small renal growth (less than 4 cm) is detected on a scan, it can often be managed without invasive treatment such as surgery. If your doctor recommended Active Surveillance with regular imaging such as ultrasound and CT, would you be willing to participate?**



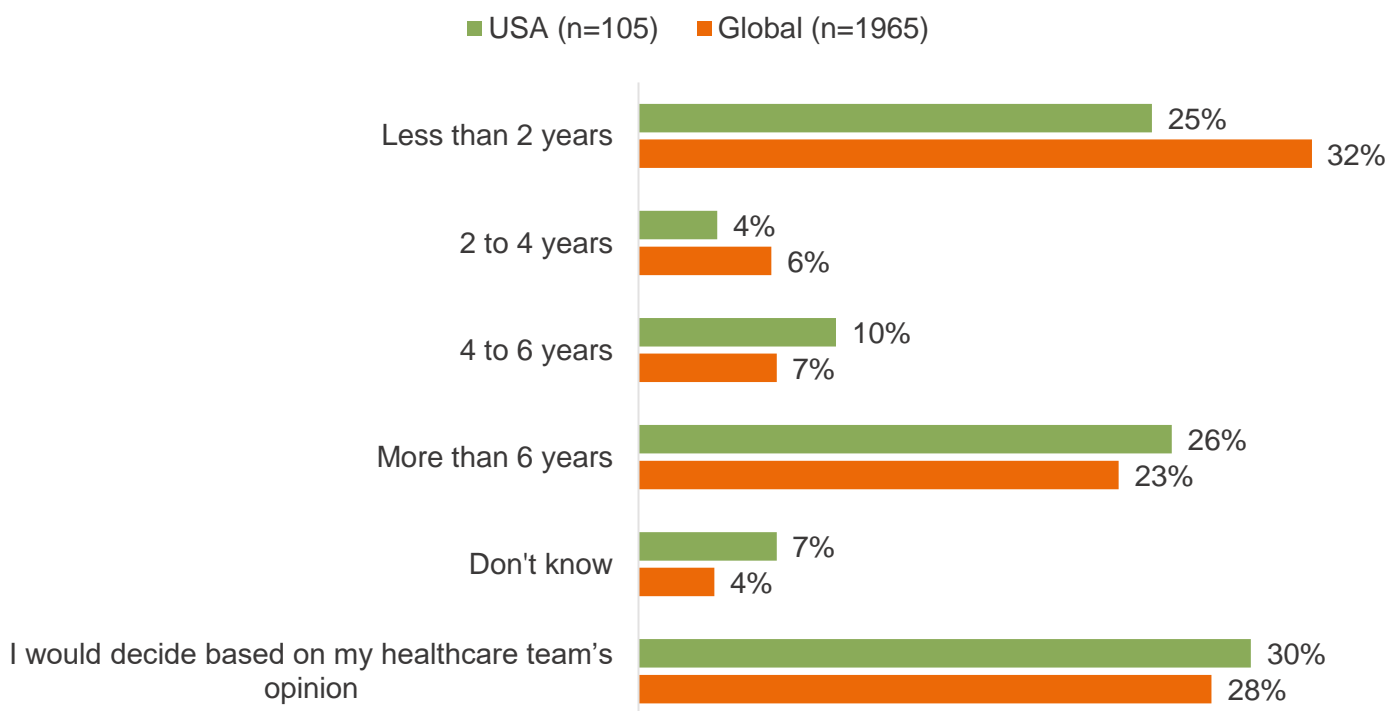
# Results: Biopsy and active surveillance for small renal mass

**Figure 32. Q21 – A biopsy of a small renal growth (less than 4 cm) might provide doctors with more information to help them form a more precise diagnosis and treatment plan for your individual case. Would you be willing to have a biopsy of the small renal growth if it might change the treatment decision?**



## Length of surveillance scanning following surgery

**Figure 33. Q22 - Following surgery for your kidney cancer or kidney growth, how long would you PREFER to have regular imaging scans (ultrasound or CT) for surveillance?**



# Results: Quality of life

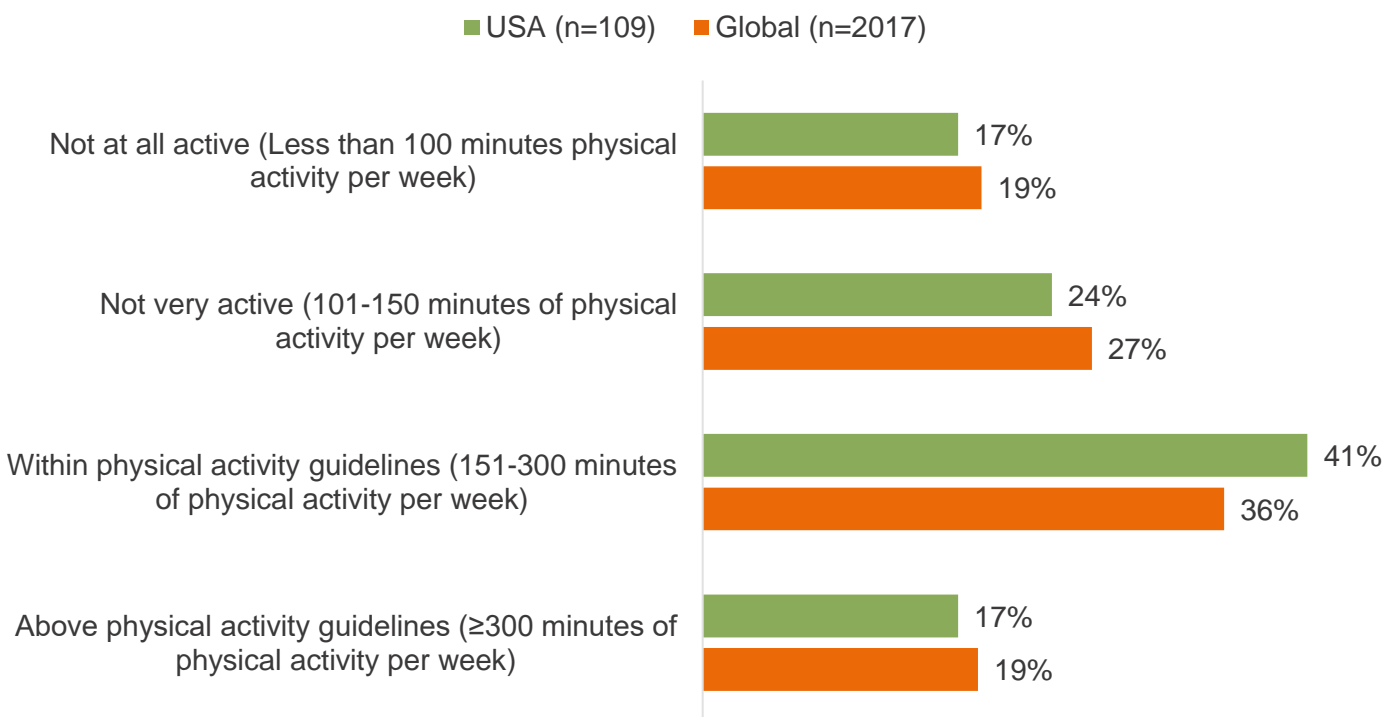
## Current level of physical activity

The data presented in this section are from questions that asked about quality of life.

In USA, **59%** (n=64) of respondents reported their current level of physical activity to be within (151-300 minutes per week) or above ( $\geq 300$  minutes per week) physical activity guidelines (Figure 34; Q23+).

This is compared to **17%** (n=19) who reported they were not at all active (less than 100 minutes of physical activity per week) and **24%** (n=26) who stated they were not very active (between 101-150 minutes of physical activity per week).

**Figure 34. Q23+ - I would describe my current level of physical activity (defined as physical activity that lasts at least 10 minutes) as:**



# Results: Quality of life

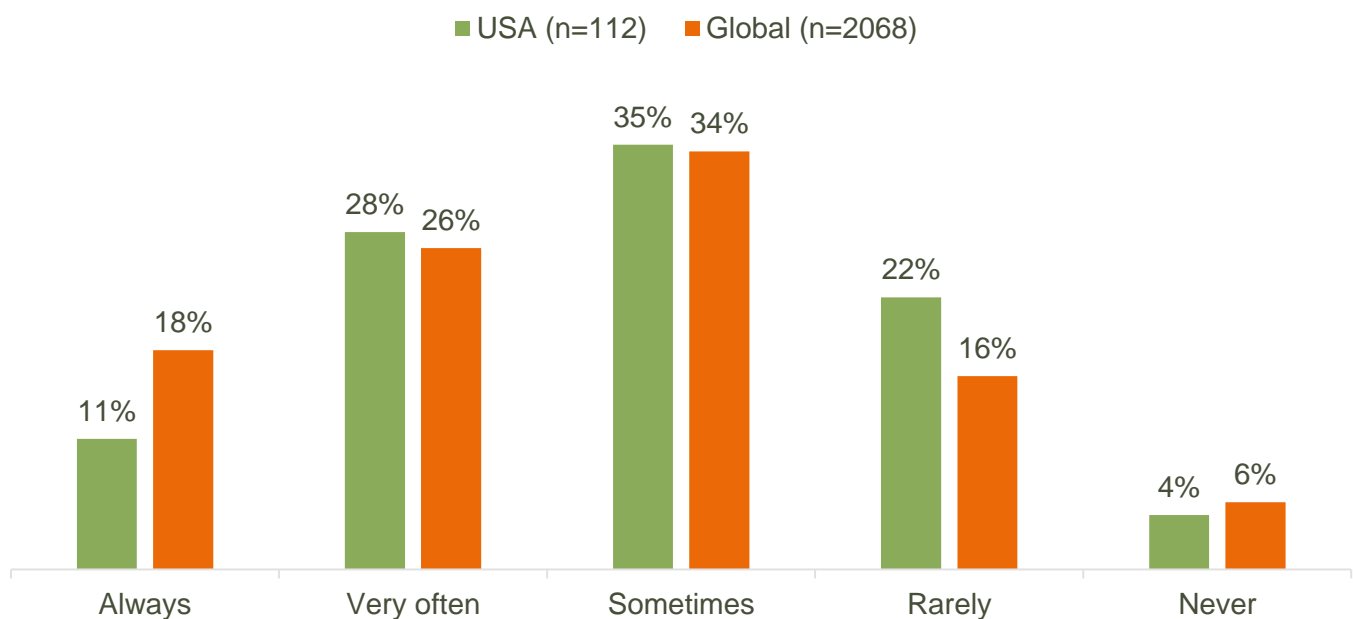
The survey asked respondents how often various symptoms, feelings and concerns had an impact on their sense of emotional well-being since their diagnosis (Figures 35 to 47; Q24, Q25).

In USA, respondents were most likely to report they always, very often or sometimes experienced:

- Fear of the cancer/growth coming back (recurrence) (**86%**, n=95) (Figure 38; Q24\_4)
- Disease-related anxiety (**79%**, n=88) (Figure 36; Q24\_2)
- General anxiety (**73%**, n=82) (Figure 35; Q24\_1)
- Fear of dying (**64%**, n=72) (Figure 37; Q24\_3)
- Sadness or Depression (**62%**, n=69) (Figure 39; Q24\_5)

## General anxiety

**Figure 35. Q24\_1 - How often have the following impacted your sense of emotional well-being since your diagnosis? – General anxiety**

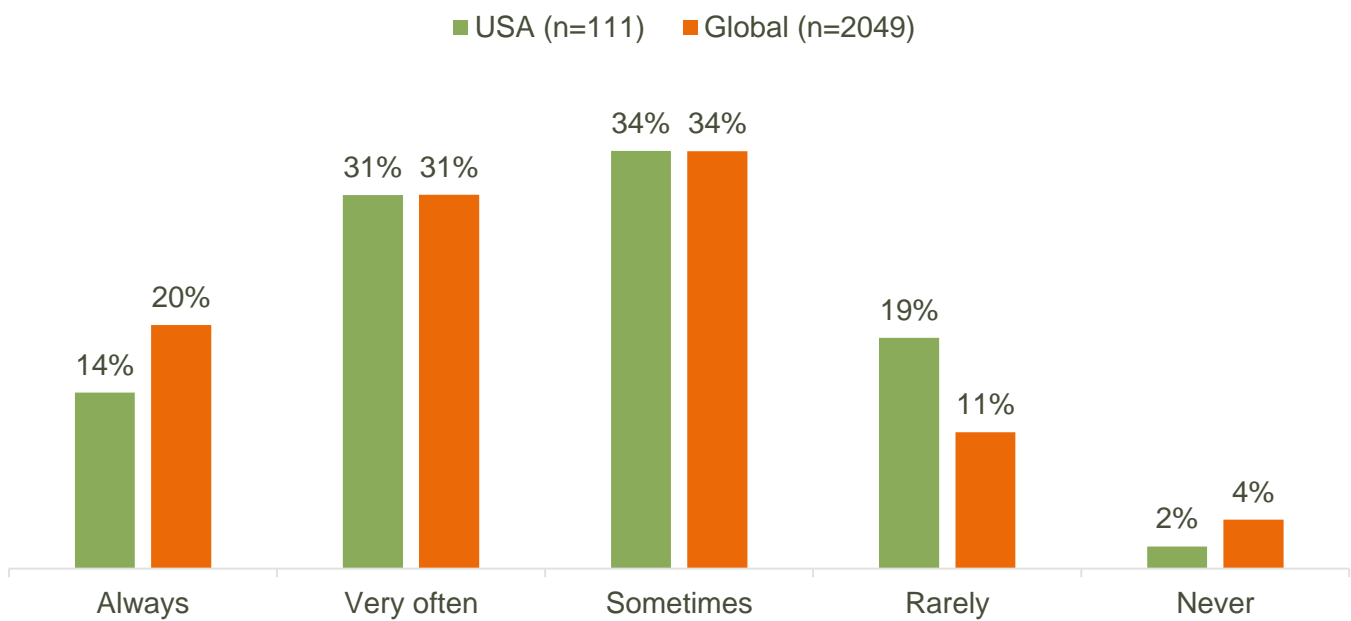




# Results: Quality of life

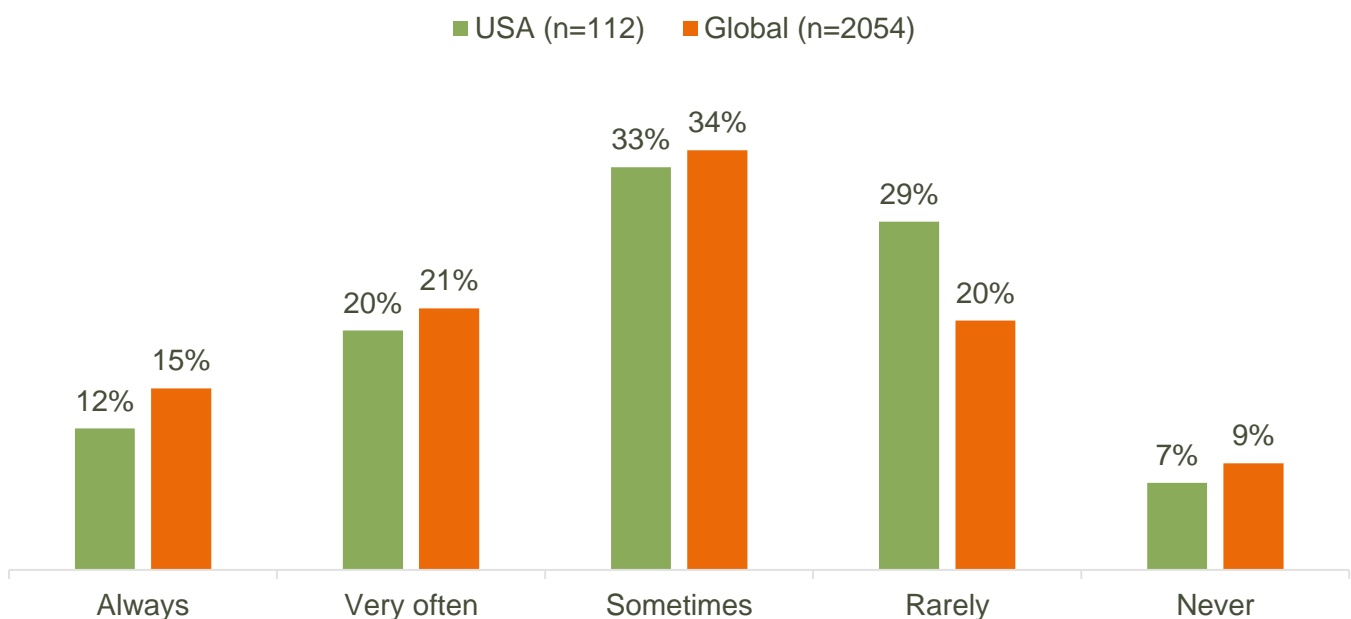
## Disease-related anxiety

Figure 36. Q24\_2 – How often have the following impacted your sense of emotional well-being since your diagnosis? – Disease-related anxiety



## Fear of dying

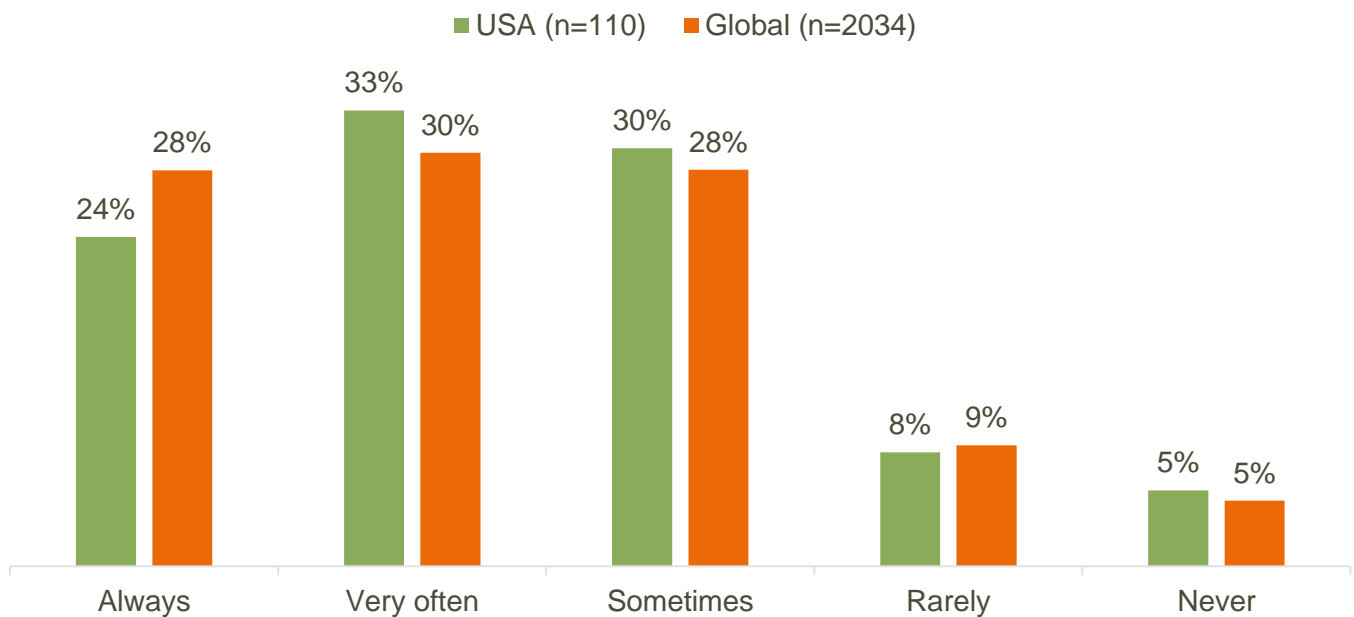
Figure 37. Q24\_3 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Fear of dying



## Results: Quality of life

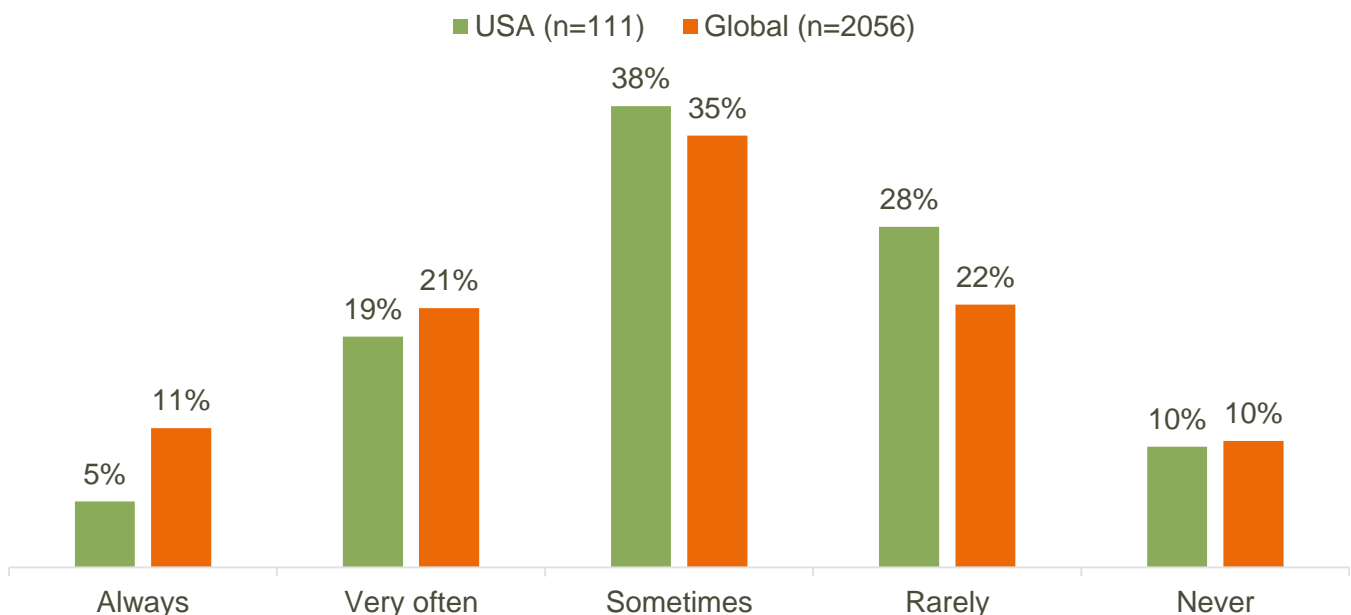
### Fear of the cancer/growth coming back (recurrence)

Figure 38. Q24\_4 – How often have the following impacted your sense of emotional well-being since your diagnosis? – Fear of the cancer/growth coming back (recurrence)



### Sadness or depression

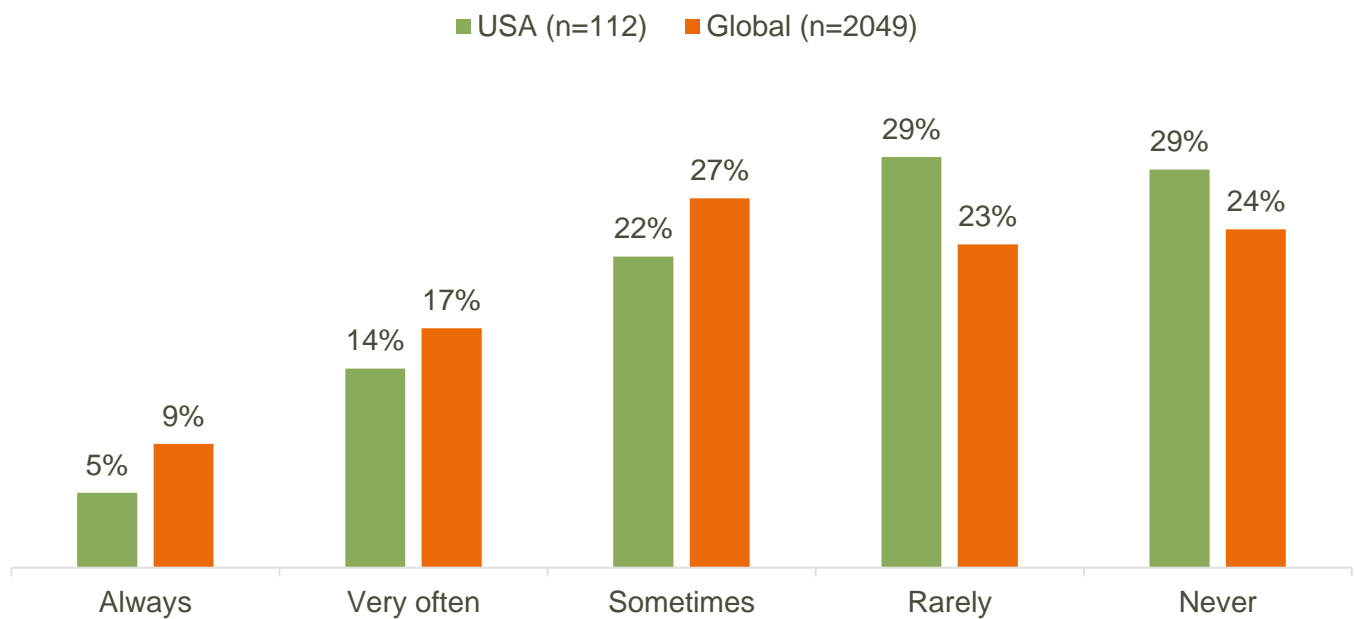
Figure 39. Q24\_5 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Sadness or depression



# Results: Quality of life

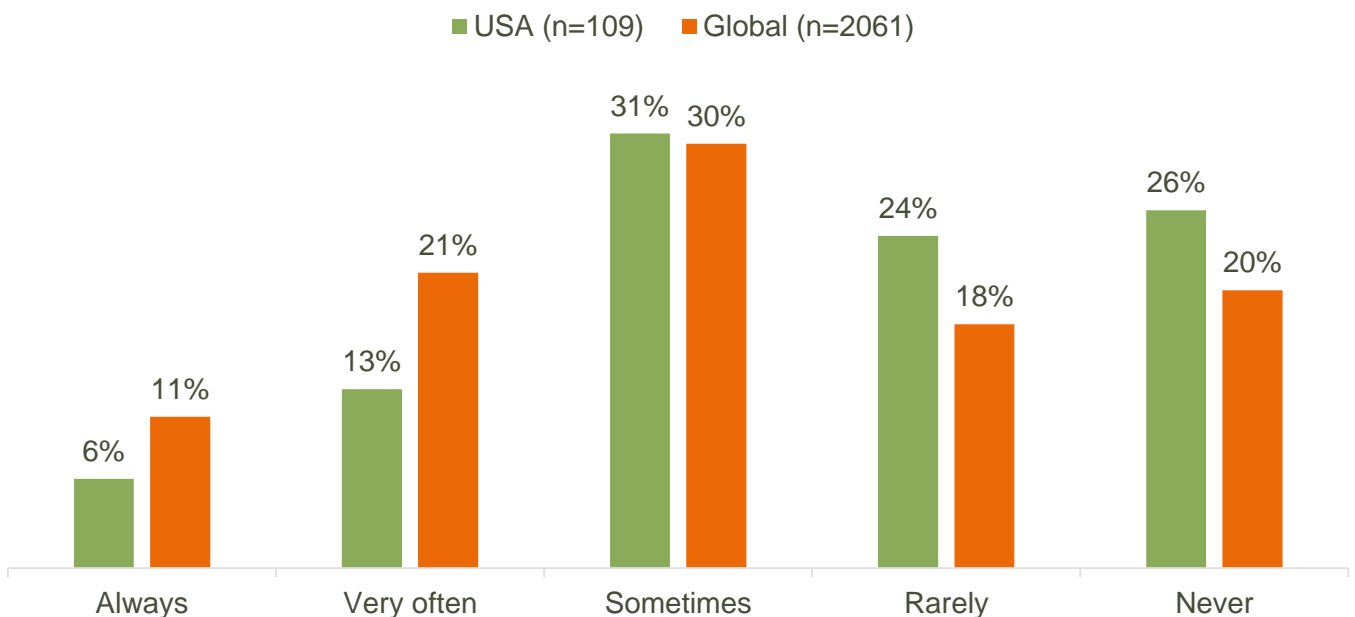
## Isolation

Figure 40. Q24\_6 – How often have the following impacted your sense of emotional well-being since your diagnosis? – Isolation



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

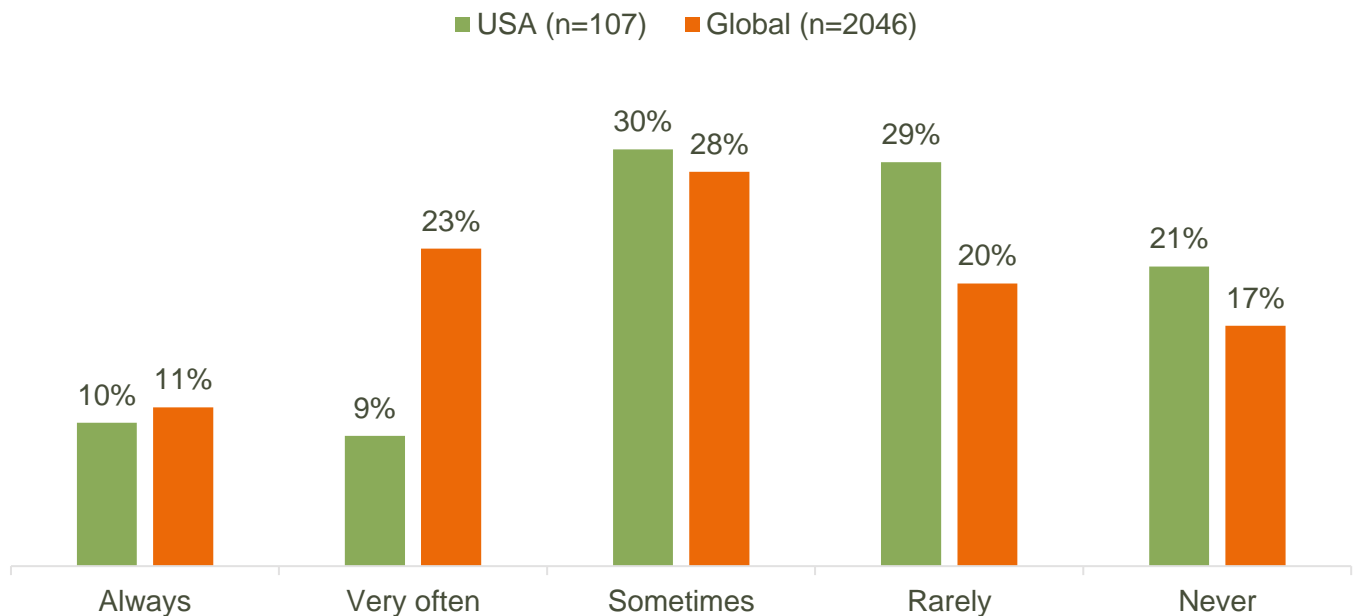
Figure 41. Q25\_1 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Changes in relationships with loved ones, friends or co-workers



## Results: Quality of life

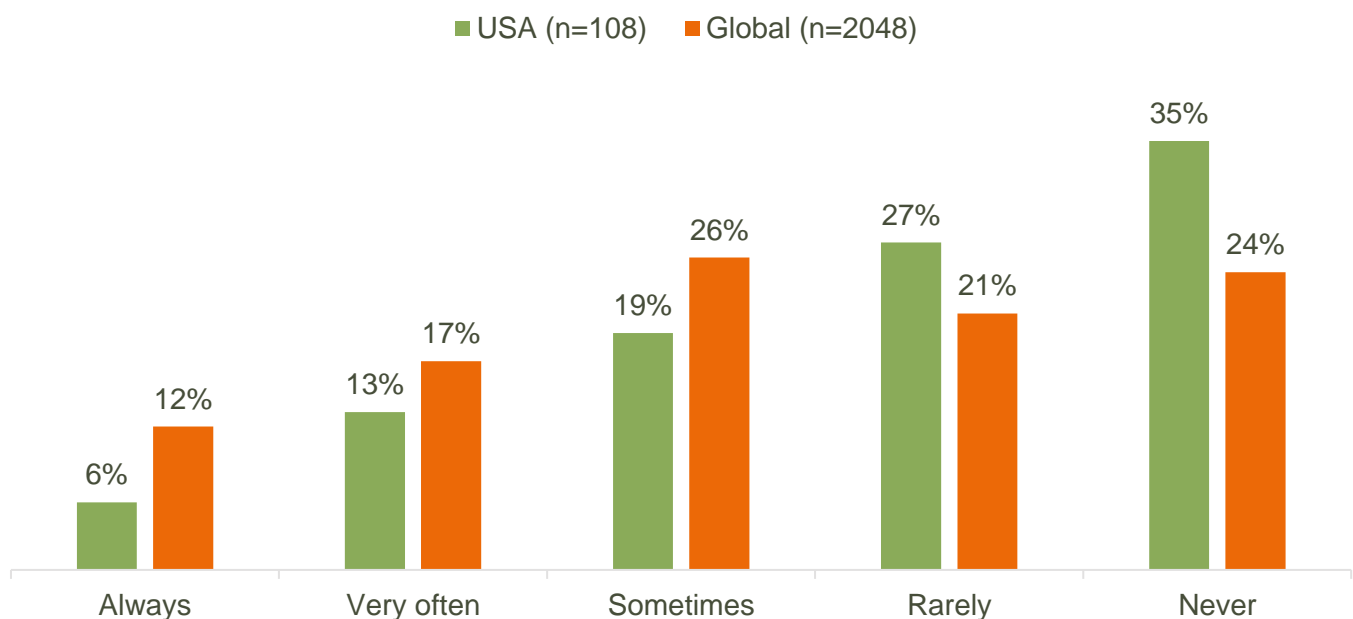
### Difficulty in daily living, on the job or in school

Figure 42. Q25\_2 – How often have the following impacted your sense of emotional well-being since your diagnosis? – Difficulty in daily living, on the job or in school



### Stress related to financial issues

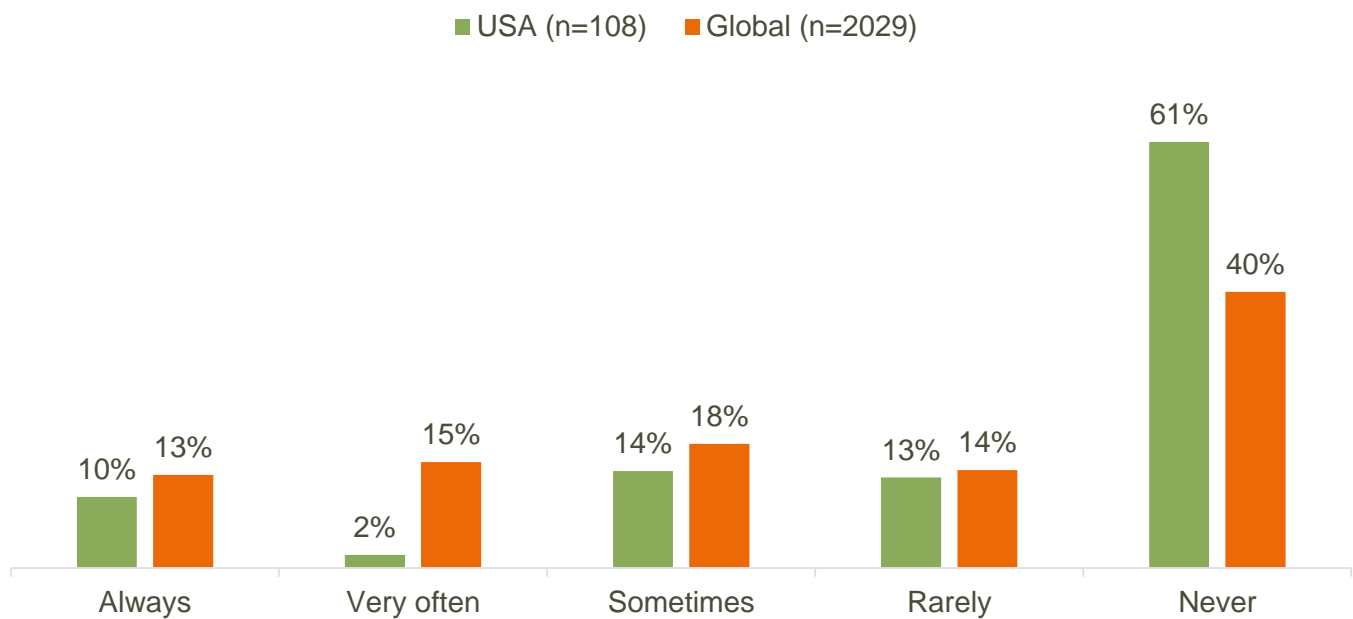
Figure 43. Q25\_3 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Stress related to financial issues



## Results: Quality of life

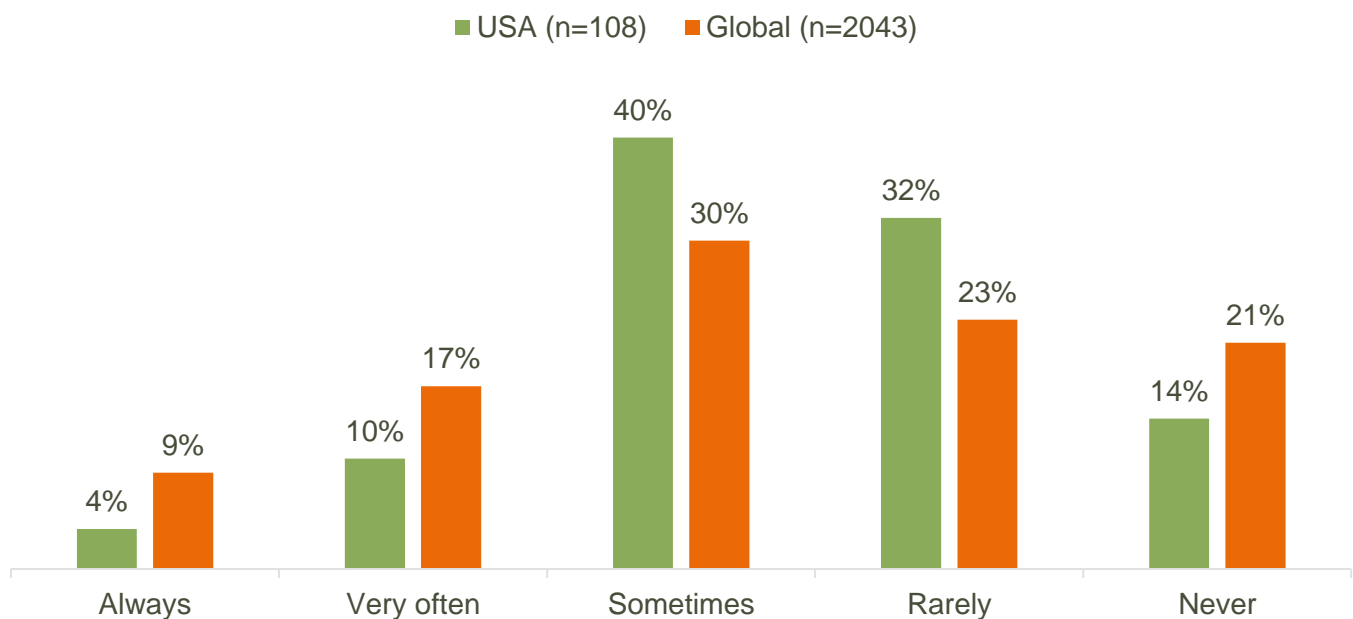
### Loss/reduction in employment

Figure 44. Q25\_4 – How often have the following impacted your sense of emotional well-being since your diagnosis? – Loss/reduction in employment



### Difficulty navigating the healthcare system

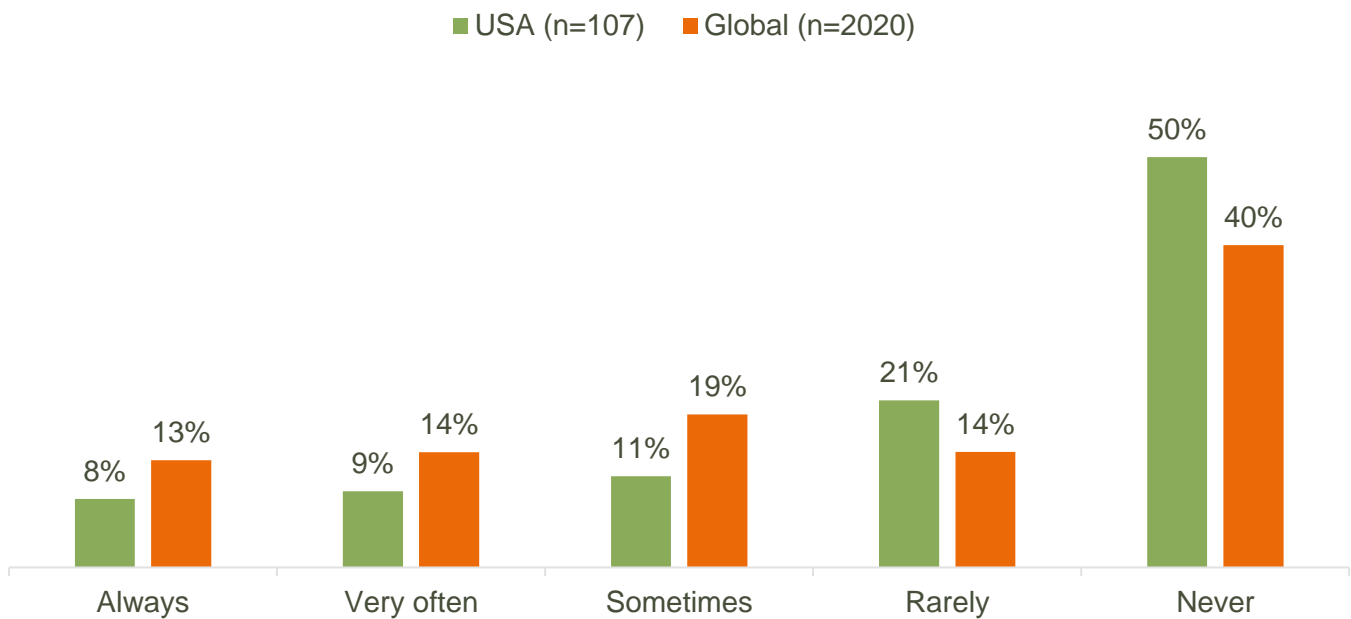
Figure 45. Q25\_5 - How often have the following impacted your sense of emotional well-being since your diagnosis? – Difficulty navigating the healthcare system



## Results: Quality of life

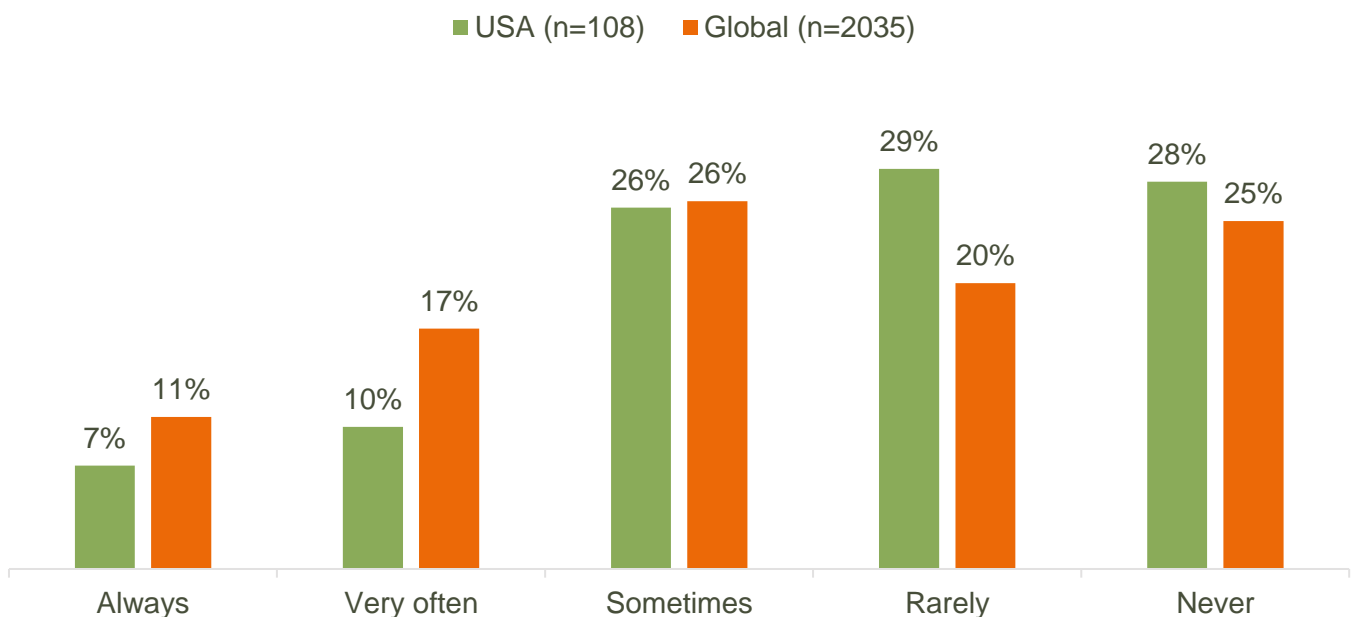
### Problems getting health or life insurance coverage

**Figure 46. Q25\_6 – How often have the following impacted your sense of emotional well-being since your diagnosis? – Problems getting health or life insurance coverage**



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

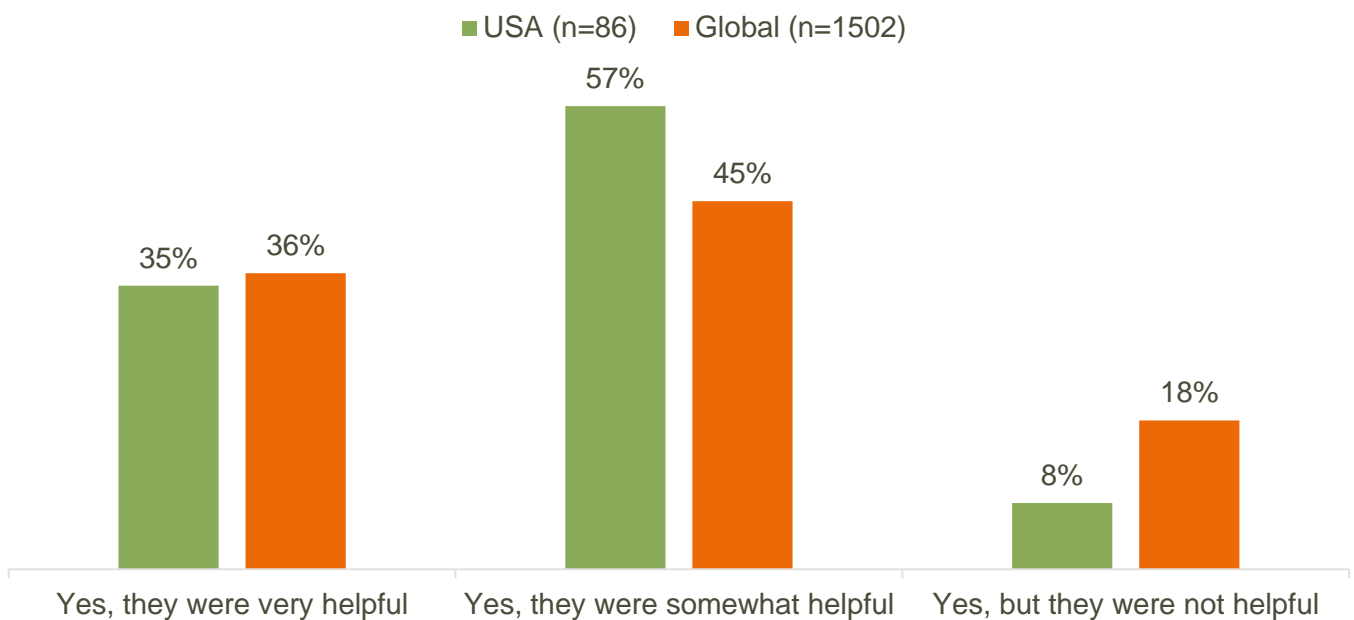
**Figure 47. Q25\_7 – How often have the following impacted your sense of emotional well-being since your diagnosis? – Concerns about body image/changes in physical appearance**



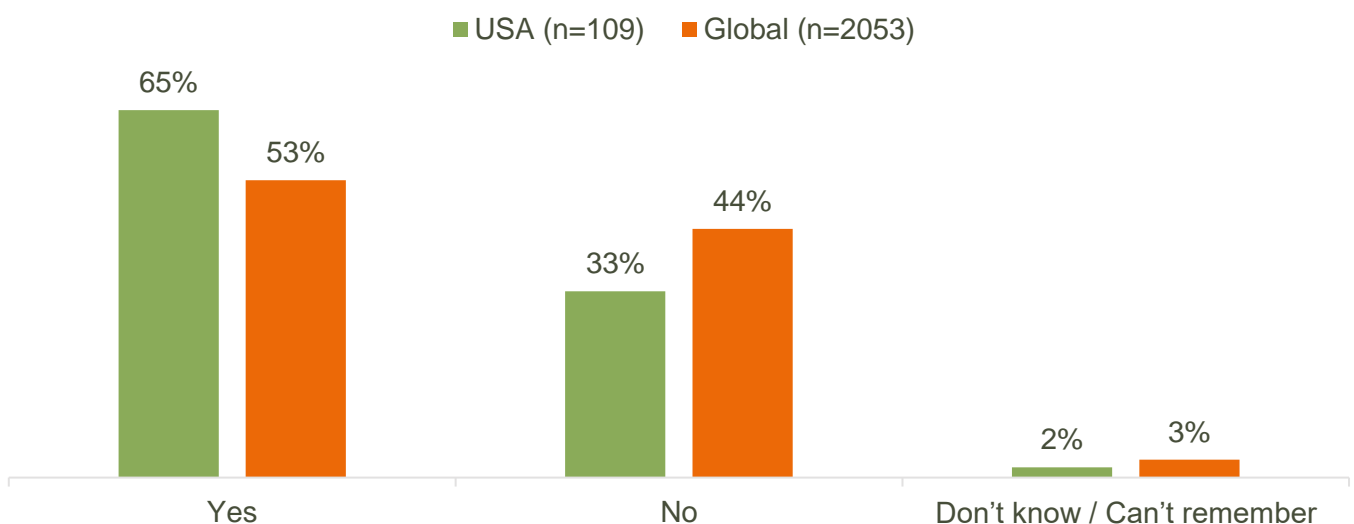
## Results: Quality of life

Respondents who reported they always, very often, or sometimes experienced a symptom, feeling or concern that impacted their sense of emotional well-being since their diagnosis (Q24; Q25) were then asked if they had ever talked to their doctor or any other healthcare professional about any of their concerns. **35%** (n=30) stated they had discussed their concerns and the doctor or healthcare professional were very helpful (Figure 48; Q27+). This is compared to **36%** (n=547) globally.

**Figure 48. Q27+ – Have you ever talked to your doctor or to any other healthcare professional about any of your concerns?**



**Figure 49. Q28 – Have you ever used a patient support group (either in person or online) to help you with your kidney cancer / growth?**



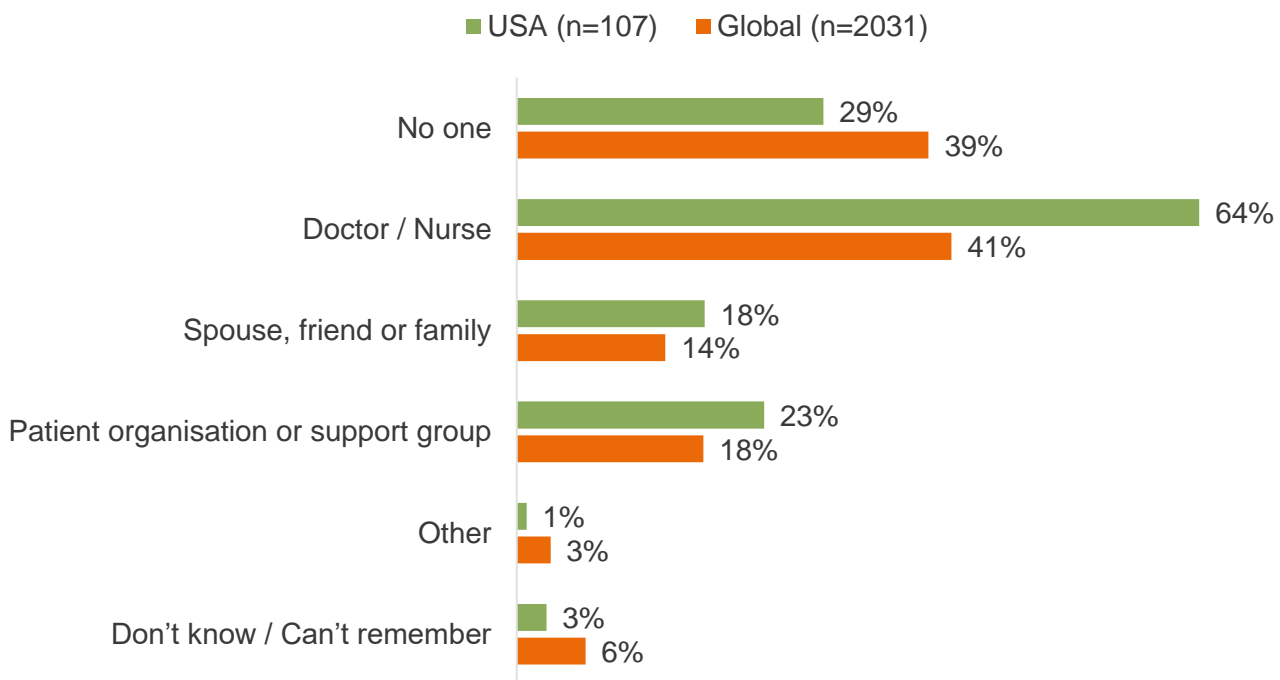
# Results: Perspectives on Kidney Cancer clinical trials

The data presented in this section are from questions that asked about Kidney Cancer clinical trials.

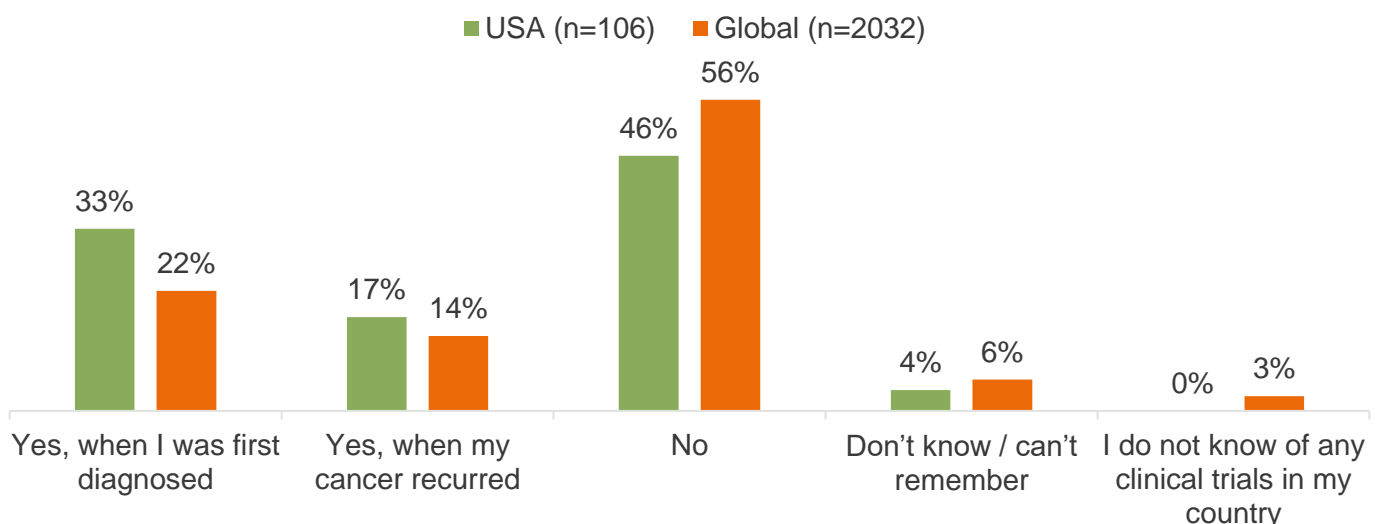
## Awareness of clinical trials

In USA, **33%** of respondents (n=35) reported they had been asked by a health professional to consider participating in a cancer clinical trial when they were first diagnosed, while **17%** (n=18) were asked when their cancer recurred (Figure 51; Q30).

**Figure 50. Q29 - Who, if anyone, has discussed cancer clinical trials with you? [multiple choice]**



**Figure 51. Q30 - Have you ever been asked by a health professional to consider participating in a cancer clinical trial?**



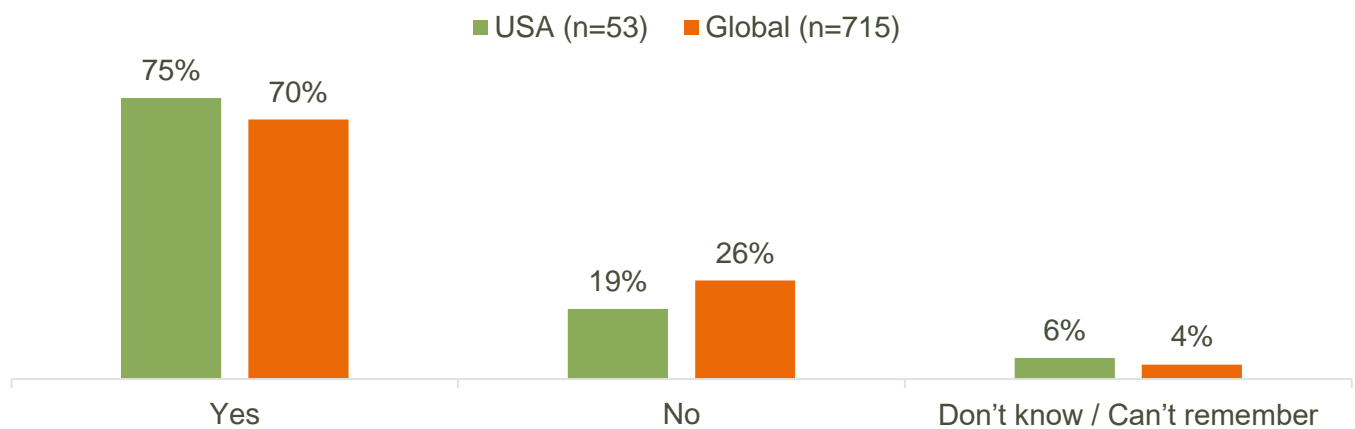


# Results: Perspectives on Kidney Cancer clinical trials

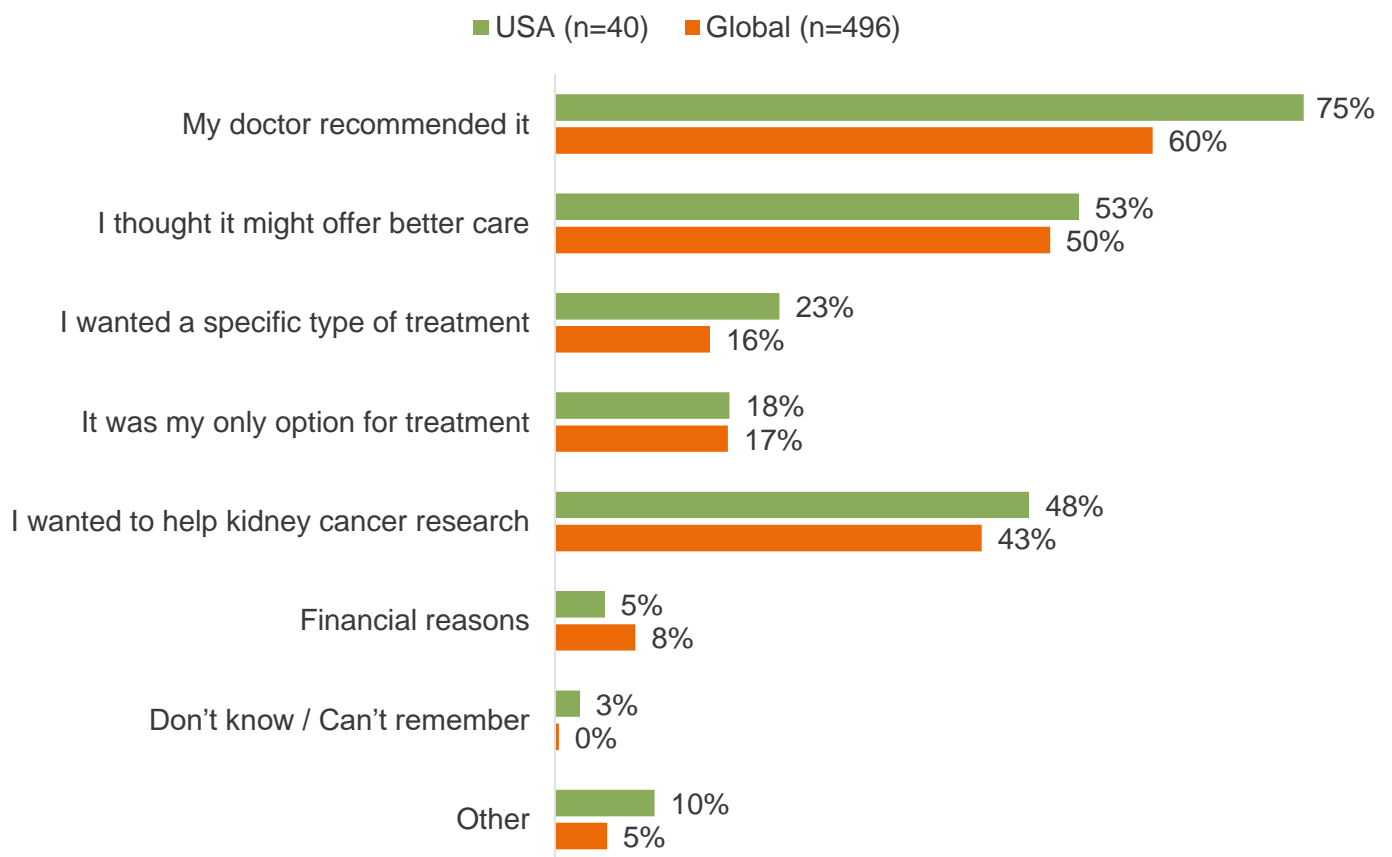
## Taking part in clinical trials

Of those who were asked to participate in a cancer clinical trial, **75%** of respondents (n=40) in USA agreed to participate, relative to **70%** (n=498) globally (Figure 52; Q31).

**Figure 52. Q31 – Did you agree to participate in the cancer clinical trial?**



**Figure 53. Q32 – Why did you agree to participate? [multiple choice]**

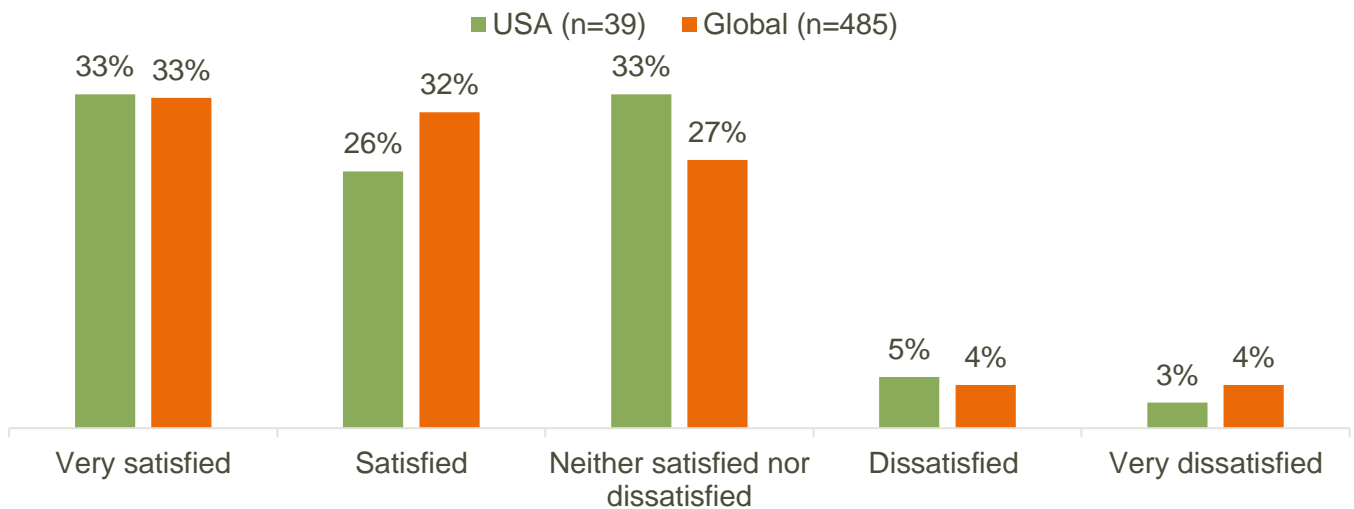


## Results: Perspectives on Kidney Cancer clinical trials

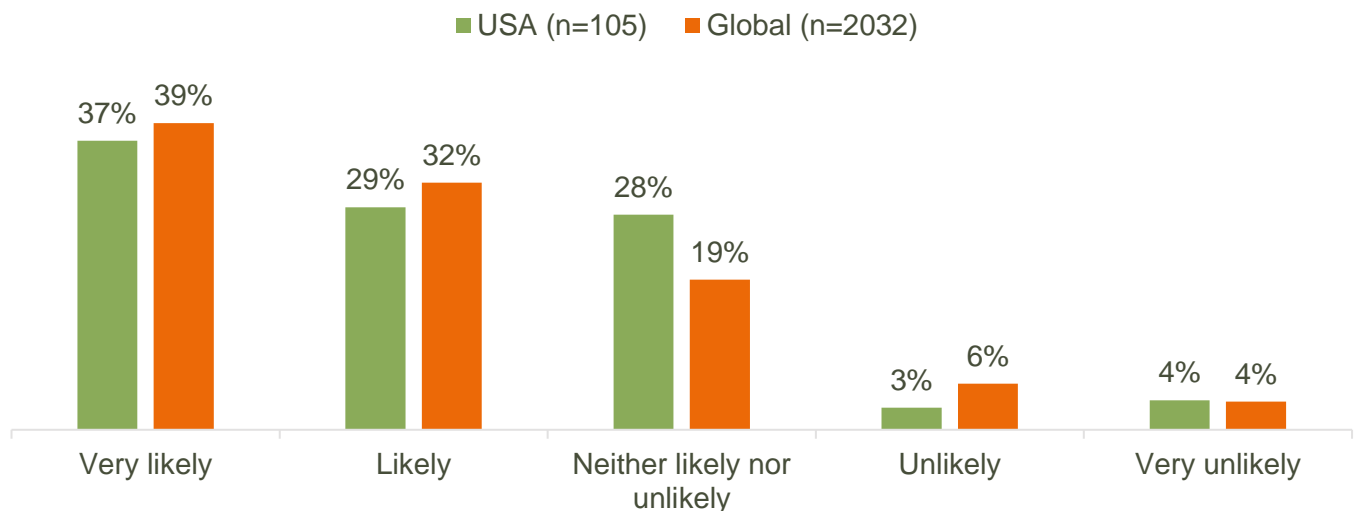
Of those who participated in a cancer clinical trial, **59%** (n=23) were very satisfied or satisfied with their overall experience. This is in comparison to **65%** (n=313) globally (Figure 54; Q33).

All respondents were asked how likely is it that they would participate in a cancer clinical trial if they were invited in future. In USA, **66%** (n=69) reported they were very likely or likely to participate, compared to **71%** (n=1445) globally (Figure 55; Q35).

**Figure 54. Q33 – How satisfied were you overall with your cancer clinical trial experience?**



**Figure 55. Q35 - In the future if you were invited, how likely is it that you would participate in a cancer clinical trial?**



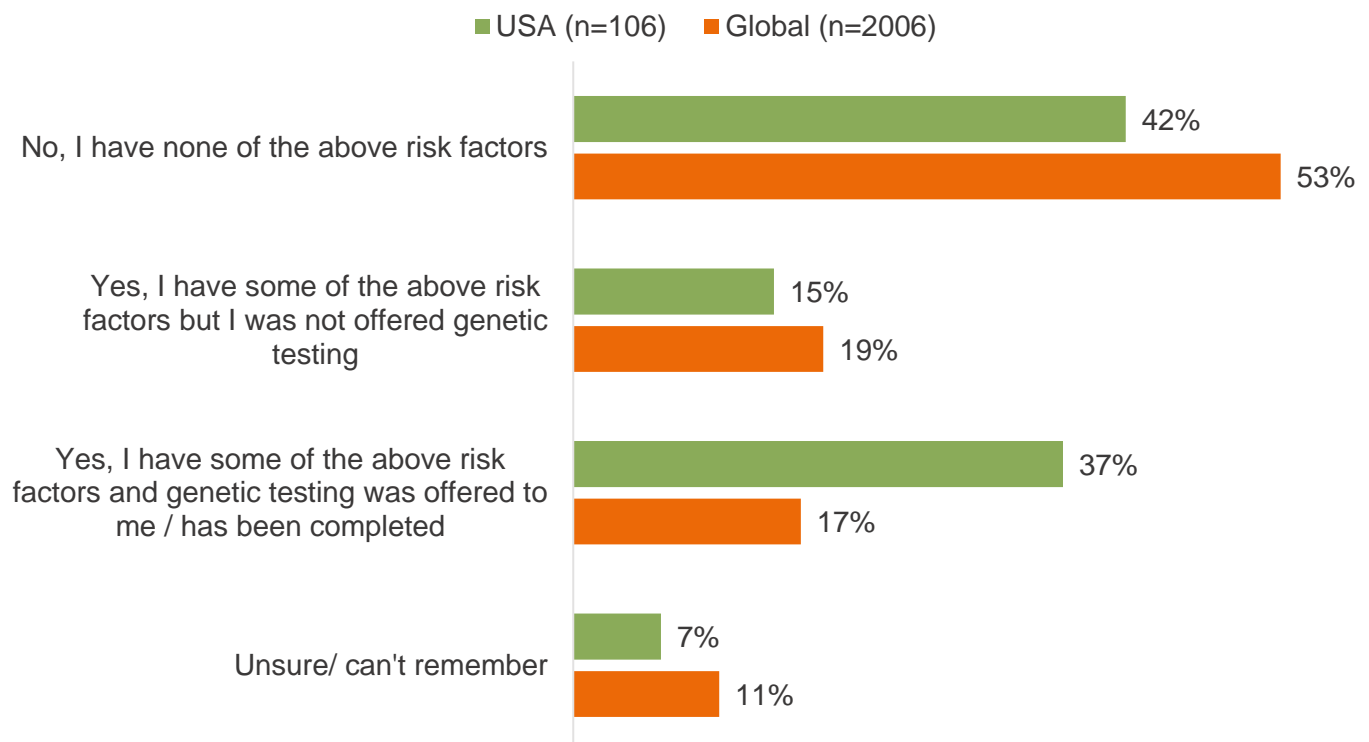
# Results: Genetic testing

A new question introduced into the 2022 survey asked respondents about genetic testing (Figure 56; Q36). Of respondents in USA:

- 42% (n=44) had none of the risk factors
- 15% (n=16) had some of the risk factors but were not offered genetic testing
- 37% (n=39) had some of the risk factors and genetic testing was offered / had been completed

**Figure 56. Q36 - Being diagnosed when you are under 46 years old, having a family history of kidney cancer or having bilateral disease may increase the chance of your kidney cancer being hereditary (caused by genetic changes passed down from parent to child). Currently less than 20% of all kidney cancers are thought to be hereditary.**

## Has anyone on your healthcare team discussed genetic testing with you?



# Detailed analysis of country data

## Positive scores

The following tables contain 'positive scores'. Positive scores are a summary measure used to compare country data against global data.

The positive score shows the percentage of respondents who gave a favourable response to applicable questions. Not all questions will have a positive score; exceptions include demographic details such as gender, ethnic group, or age. Higher scores indicate more positive results.

Example score table:

Would you be willing to have a biopsy?	Your country	
Base (all respondents)	200	100.0%
Strongly disagree	20	10.0%
Disagree	35	17.5%
Neither agree nor disagree	45	22.5%
<b>Agree</b>	<b>35</b>	<b>17.5%</b>
<b>Strongly agree</b>	<b>65</b>	<b>32.5%</b>

Positive responses are combined



Resulting in **50%** of respondents (n=100) agreed to have a biopsy.

## Significance testing

We identify questions where there are significant differences between your country and global average. By 'significant' difference, we mean the scores between your country and the global results are statistically significant with a confidence level of 95%. We are therefore reasonably confident that the result reflects a real difference.

The calculation used to test the statistical significance of scores is the Agresti-Coull modification of the "z-test". The Z-test calculates the differences between two proportions. Any result where the value of Z is greater than 1.96 is marked as "statistically significant".

In the following tables, coloured cells show where your positive score is significantly different to the global average. Green cells indicate a significantly higher score than the global average, and red cells show a significantly lower score than the global average.

Please note that there are differences in kidney cancer care provision between countries, as well as differences in the profile of respondents globally. For this reason, caution should be taken when comparing country results to global data.

## Comparisons to global findings

Key: ■ significantly higher than global ■ significantly lower than global, “\*” = suppressed

		Global comparison			
		USA		Global	
Section	Question	n	score	n	score
Diagnosis	Informed of sub-type of kidney cancer or growth when first diagnosed (Q8)	109	35%	1979	36%
	Diagnosed within 3 months or less from time patient first thought something might be wrong (Q10)	109	73%	1968	71%
	Stage of cancer completely explained when planning treatments (Q11_1)	107	50%	2074	48%
	Sub-type of cancer completely explained when planning treatments (Q11_2)	101	39%	1853	33%
	Treatment options completely explained when planning treatments (Q11_3)	107	49%	2001	54%
	Treatment recommendations completely explained when planning treatments (Q11_4)	107	54%	1969	55%
	Risk of recurrence completely explained when planning treatments (Q11_5)	101	36%	1923	34%
	Likelihood of surviving cancer beyond five years completely explained when planning treatments (Q11_6)	102	25%	1925	28%
Developing a treatment plan	Definitely involved in decisions about treatment plan as much as wanted to be (Q13)	111	<b>68%</b>	2051	48%

## Comparisons to global findings

Key: ■ significantly higher than global ■ significantly lower than global, “\*” = suppressed

		Global comparison			
		USA		Global	
Section	Question	n	score	n	score
Your care and treatment	Experienced no barriers that affected treatment choices (Q15)	109	59%	2085	46%
Your care today	Understands surgical options (Q18_1)	102	75%	1887	72%
	Understands immunotherapy options (Q18_2)	101	73%	1723	53%
	Understands targeted therapy options (pills or tablets) (Q18_3)	102	65%	1707	52%
	Understands radiation therapy options (Q18_4)	99	49%	1639	46%
	Understands ablative therapy options (cryoablation or radiofrequency ablation) (Q18_5)	96	32%	1633	32%
	Understands active surveillance (Q18_6)	98	63%	1747	52%
	Understands adjuvant therapy (treatment aimed at reducing the chance of recurrence after surgery) (Q18_7)	84	42%	1608	29%
	Understands palliative/ supportive care (Q19_1)	104	50%	1795	51%
	Understands the importance of good nutrition for my well-being (Q19_2)	105	58%	1928	58%
	Understands the importance of lifestyle choices for my wellbeing (e.g. avoiding smoking, being active) (Q19_3)	105	80%	1936	71%
	Understands complementary therapies (e.g. meditation, etc.) (Q19_4)	99	37%	1828	38%
	Understands local guidelines for kidney cancer care and follow up (Q19_5)	99	51%	1866	43%

## Comparisons to global findings

Key: ■ significantly higher than global ■ significantly lower than global, “\*” = suppressed

		Global comparison			
		USA		Global	
Section	Question	n	score	n	score
Quality of life	Physical activity within or above physical activity guidelines (=> 151 minutes per week) (Q23)	109	59%	2017	54%
	Never/ rarely experienced general anxiety since diagnosis (Q24_1)	112	27%	2068	21%
	Never/ rarely experienced disease-related anxiety since diagnosis (Q24_2)	111	21%	2049	15%
	Never/ rarely experienced fear of dying since diagnosis (Q24_3)	112	36%	2054	29%
	Never/ rarely experienced fear of the cancer/growth coming back (recurrence) since diagnosis (Q24_4)	110	14%	2034	13%
	Never/ rarely experienced sadness or depression since diagnosis (Q24_5)	111	38%	2056	32%
	Never/ rarely experienced isolation since diagnosis (Q24_6)	112	58%	2049	47%
	Never/ rarely experienced changes in relationships with loved ones, friends or co-workers since diagnosis (Q25_1)	109	50%	2061	37%
	Never/ rarely experienced difficulty in daily living, on the job or in school since diagnosis (Q25_2)	107	50%	2046	38%
	Never/ rarely experienced stress related to financial issues since diagnosis (Q25_3)	108	62%	2048	45%
	Never/ rarely experienced loss/reduction in employment since diagnosis (Q25_4)	108	74%	2029	54%
	Never/ rarely experienced difficulty navigating the healthcare system since diagnosis (Q25_5)	108	46%	2043	44%
	Never/ rarely experienced problems getting health or life insurance coverage since diagnosis (Q25_6)	107	71%	2020	54%
	Never/ rarely experienced concerns about body image/changes in physical appearance since diagnosis (Q25_7)	108	56%	2035	45%
Doctor or healthcare professional very helpful when talking about concerns (Q27)	86	35%	1502	36%	

## Comparisons to global findings

Key: ■ significantly higher than global ■ significantly lower than global, "\*" = suppressed

		Global comparison			
		USA		Global	
Section	Question	n	score	n	score
Cancer clinical trials	Very satisfied or satisfied with overall experience of cancer clinical trial (Q33)	39	59%	485	65%



# Benchmarking country results to global results

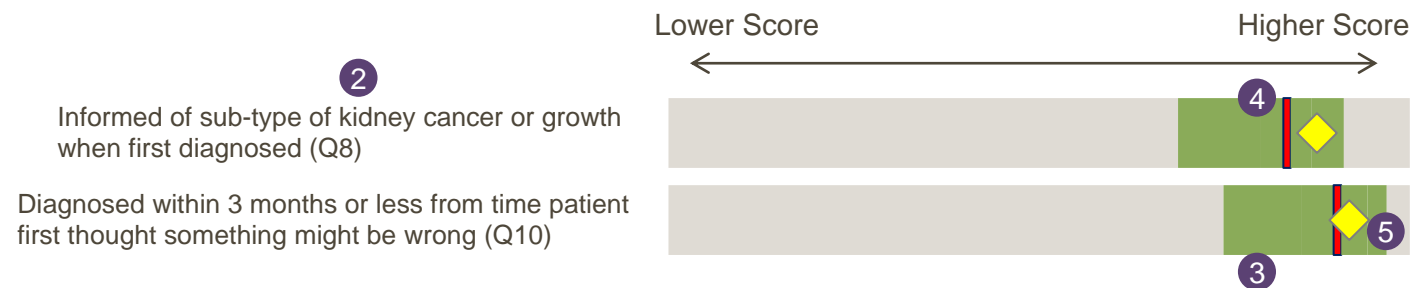
## Benchmarking charts

Benchmarking charts display how the positive score for your country compares to the range of scores across other countries. These can be useful for highlighting where there is room for improvement.

Please note that there are differences in kidney cancer care provision between countries, as well as differences in the profile of respondents globally. For this reason, caution should be taken when comparing country results to global data.

## How to interpret the charts

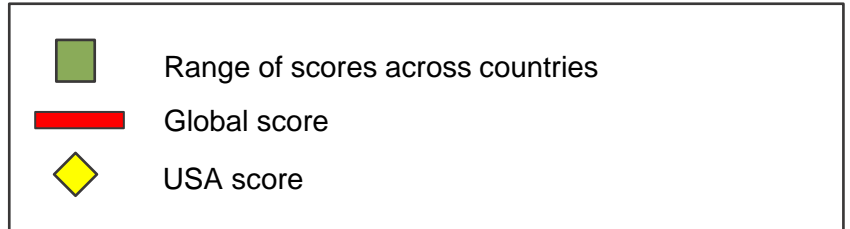
### Diagnosis (example data) 1



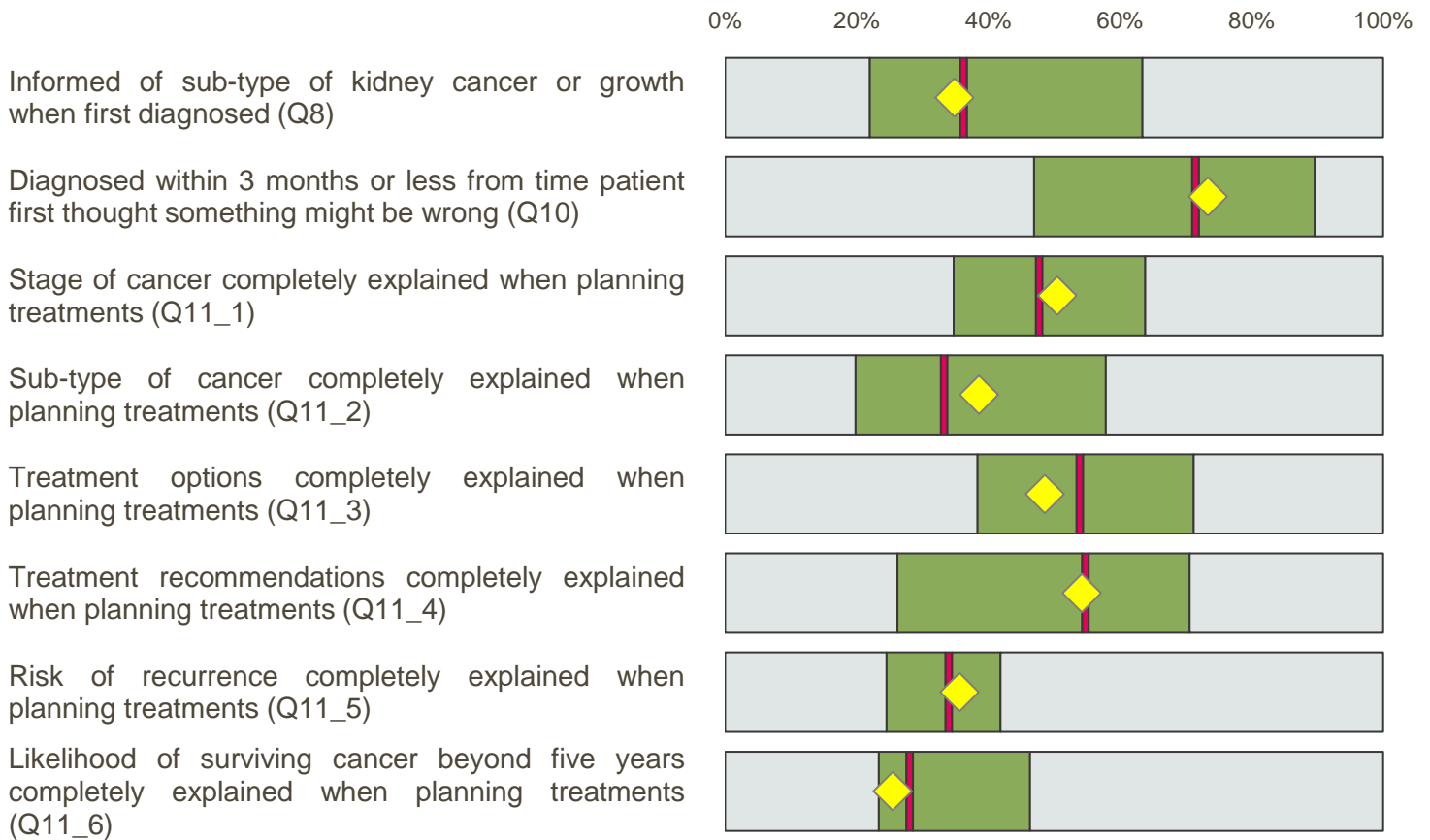
### KEY

1. Section of the questionnaire
2. Question number and positive score text (derived from survey question)
3. Green bar: range of positive scores for all countries
4. Red line: global average score
5. Yellow diamond: the score for your country

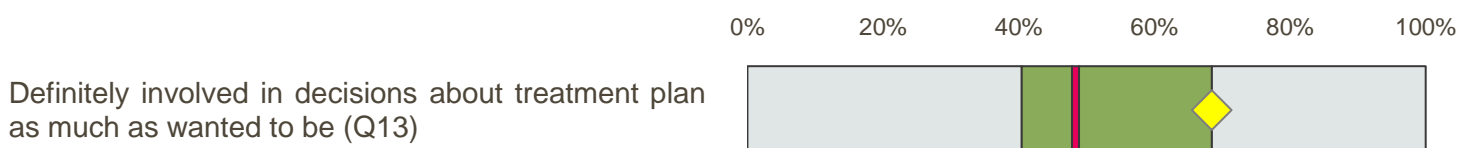
# Benchmarking charts



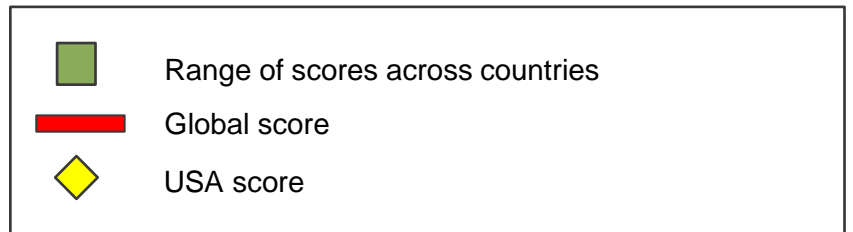
## Diagnosis



## Developing a treatment plan

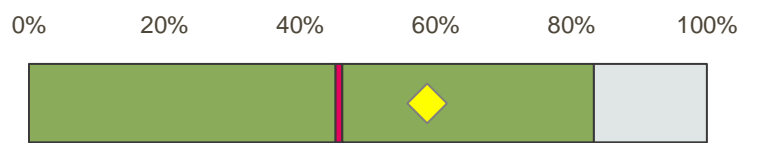


# Benchmarking charts



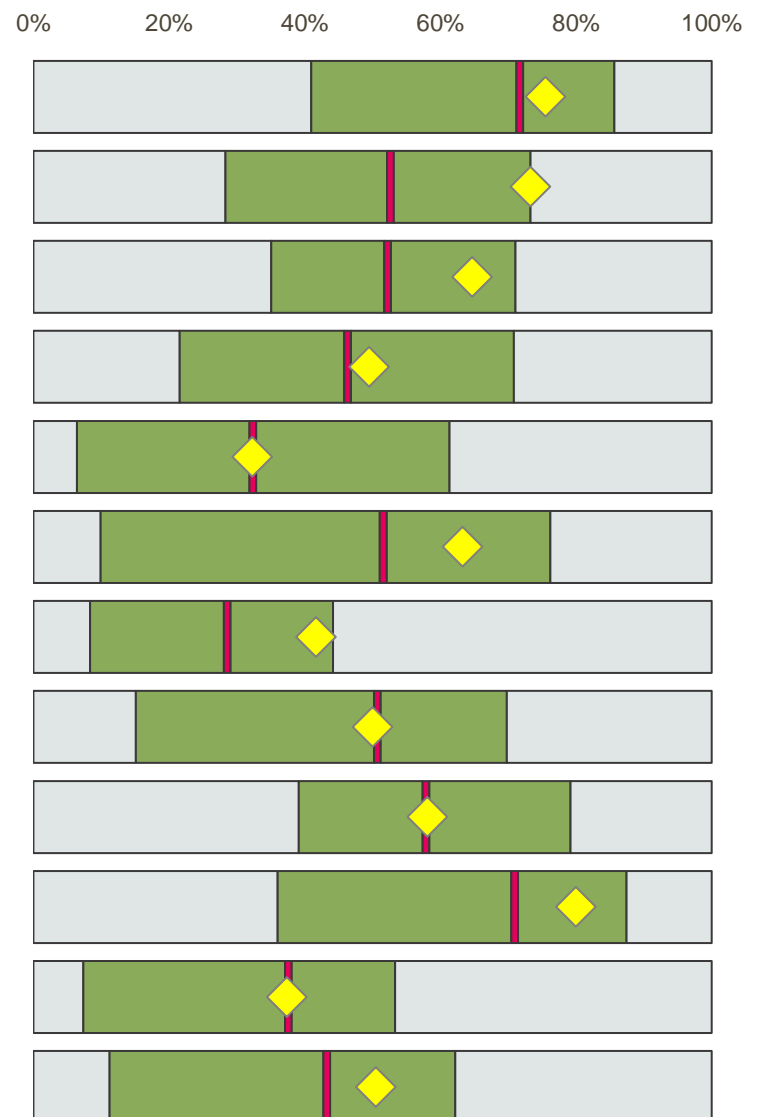
## Your care and treatment

Experienced no barriers that affected treatment choices (Q15)

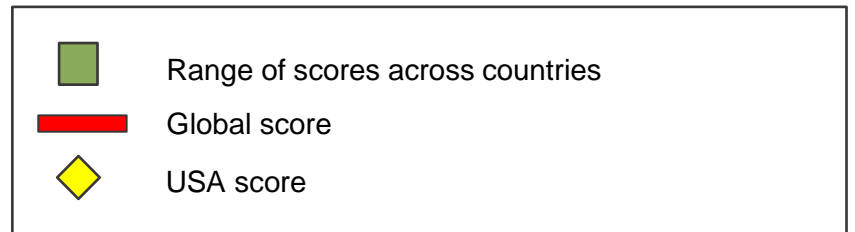


## Your care today

- Understands surgical options (Q18\_1)
- Understands immunotherapy options (Q18\_2)
- Understands targeted therapy options (pills or tablets) (Q18\_3)
- Understands radiation therapy options (Q18\_4)
- Understands Ablative therapy options (cryoablation or radiofrequency ablation) (Q18\_5)
- Understands Active Surveillance (Q18\_6)
- Understands Adjuvant therapy (Q18\_7)
- Understands palliative/ supportive care (Q19\_1)
- Understands the importance of good nutrition for my well-being (Q19\_2)
- Understands the importance of lifestyle choices for my wellbeing (Q19\_3)
- Understands complementary therapies (e.g. meditation, etc.) (Q19\_4)
- Understands local guidelines for kidney cancer care and follow up (Q19\_5)



# Benchmarking charts

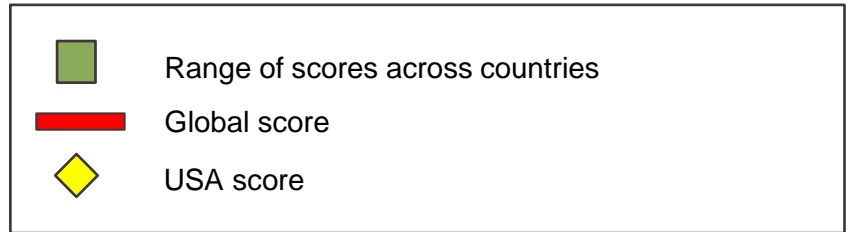


## Quality of life



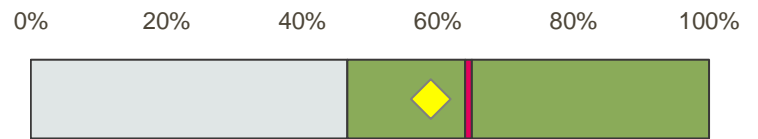
N.B. Full reporting text: Q25\_1 Never/ rarely experienced changes in relationships with loved ones, friends or co-workers since diagnosis; Q25\_7 Never/ rarely experienced concerns about body image/changes in physical appearance since diagnosis

## Benchmarking charts



### Cancer clinical trials

Very satisfied or satisfied with overall experience of cancer clinical trial (Q33)





## Conclusions

This report presents data from residents of USA from the International Kidney Cancer Coalition (IKCC) biennial Global Survey 2022, 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, Eisai, Exelixis, Ipsen, and MSD\* 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 2022 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.

\*Partial Funding



## Appendices

1. Frequency Tables – USA (Available as a separate document)
2. Methodology (Available as a separate document)
3. Questionnaire (Available as a separate document)

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

- International Kidney Cancer Coalition Survey 2022 – Global
- International Kidney Cancer Coalition Survey 2022 – Country

*Country specific reports where respondent numbers are greater or equal to 90. These include:*

- Canada
- England
- France
- Germany
- India
- Japan
- Mexico
- Republic of Korea
- South Africa
- USA



## 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

Legally incorporated as a 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](http://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 UK General Data Protection Regulation, the Data Protection Act 2018 and the Market Research Society's (MRS) Code of Conduct.