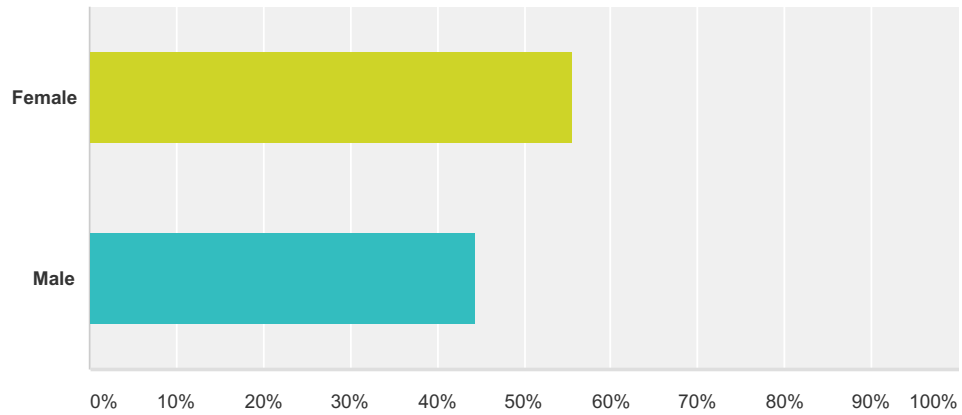


Q1 Are you male or female?

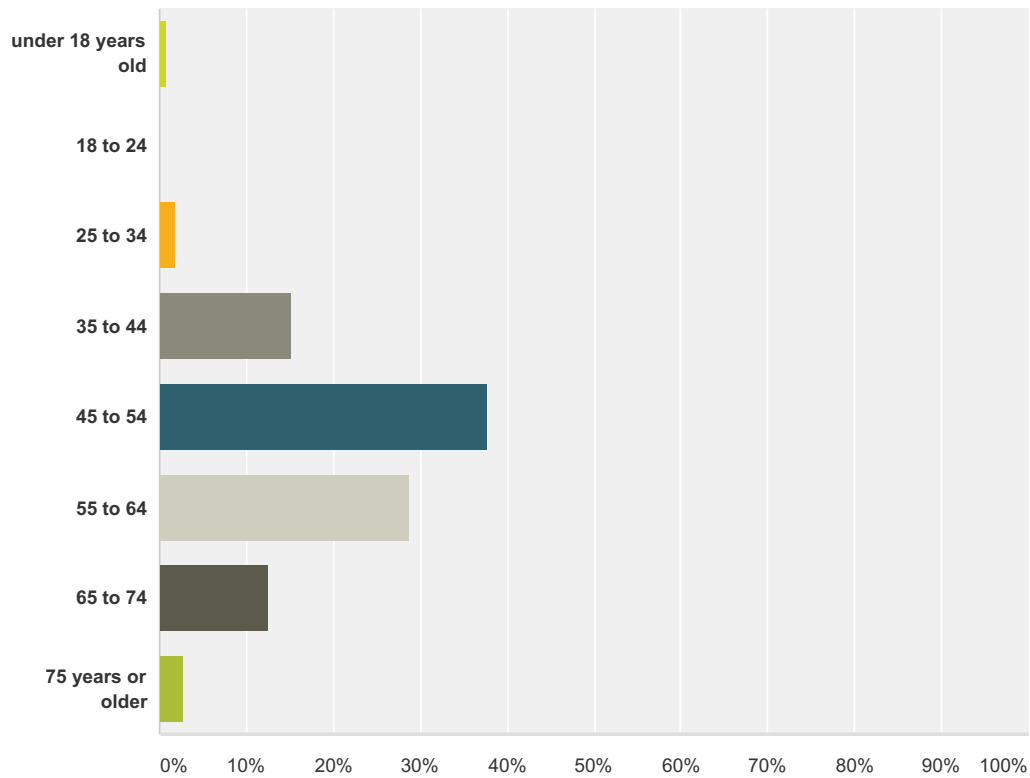
Answered: 110 Skipped: 1



Answer Choices	Responses
Female	55.45% 61
Male	44.55% 49
Total Respondents: 110	

Q2 Which age range do you fit into?

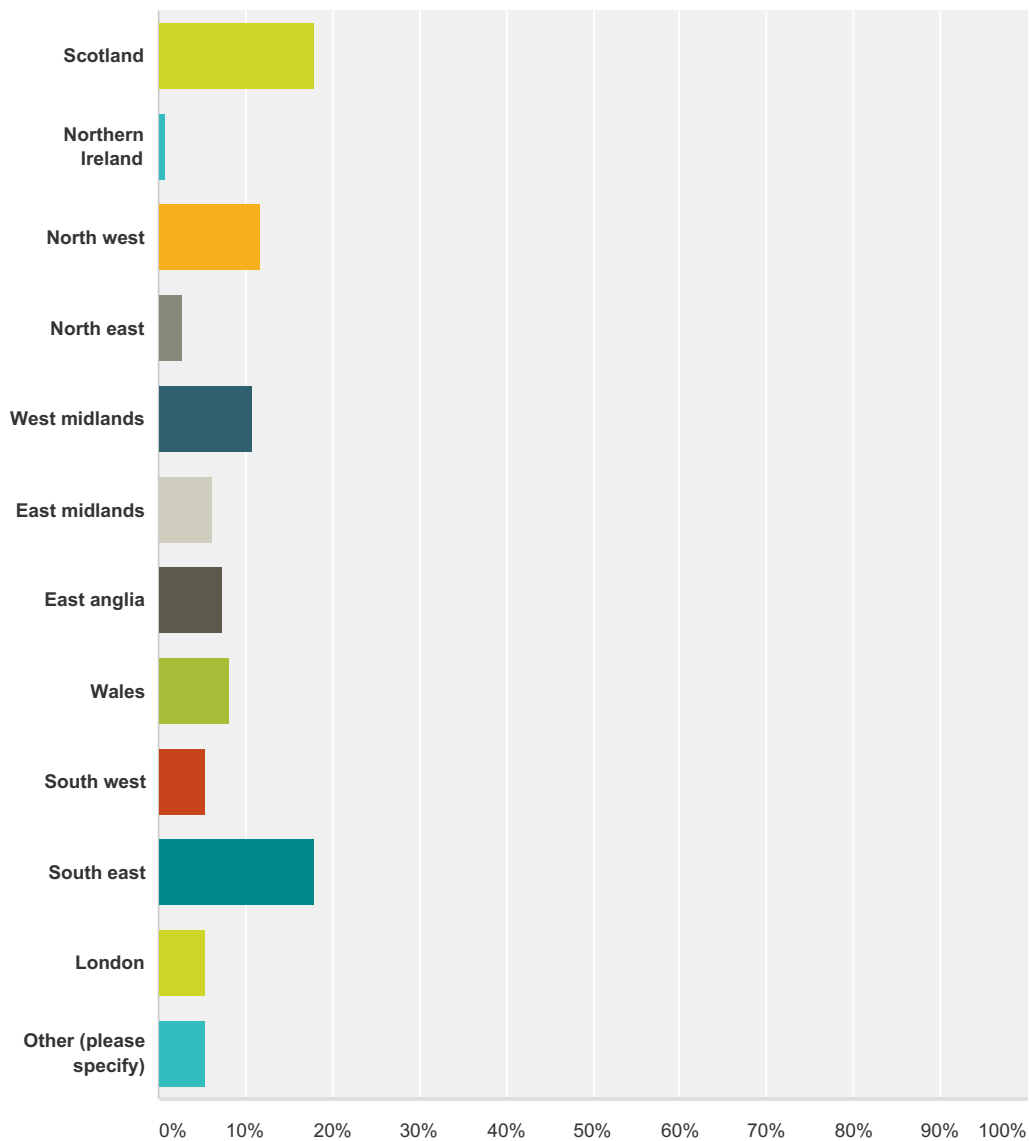
Answered: 111 Skipped: 0



Answer Choices	Responses	
under 18 years old	0.90%	1
18 to 24	0.00%	0
25 to 34	1.80%	2
35 to 44	15.32%	17
45 to 54	37.84%	42
55 to 64	28.83%	32
65 to 74	12.61%	14
75 years or older	2.70%	3
Total		111

Q3 Which region of the UK do you live in?

Answered: 111 Skipped: 0

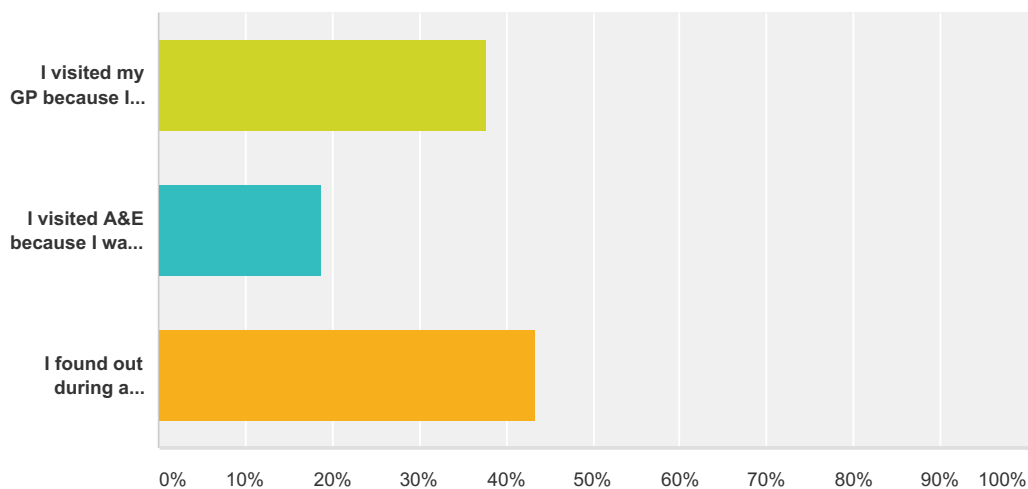


Answer Choices	Responses
Scotland	18.02% 20
Northern Ireland	0.90% 1
North west	11.71% 13
North east	2.70% 3
West midlands	10.81% 12
East midlands	6.31% 7
East anglia	7.21% 8
Wales	8.11% 9

South west	5.41%	6
South east	18.02%	20
London	5.41%	6
Other (please specify)	5.41%	6
Total		111

Q4 How did you find out that you had kidney cancer?

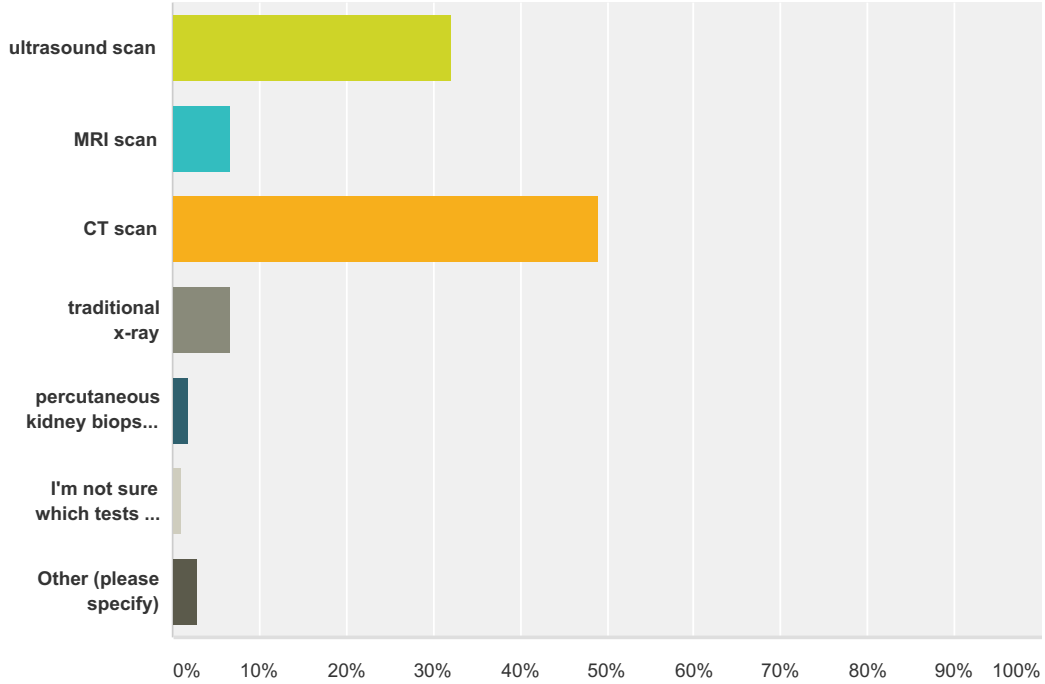
Answered: 106 Skipped: 5



Answer Choices	Responses	
I visited my GP because I was feeling unwell and was sent for more tests	37.74%	40
I visited A&E because I was feeling unwell and was sent for more tests	18.87%	20
I found out during a medical scan or test that was unrelated to kidney cancer	43.40%	46
Total		106

Q5 Which type of scan or test did you receive to first diagnose your kidney cancer? (Tick all that apply)

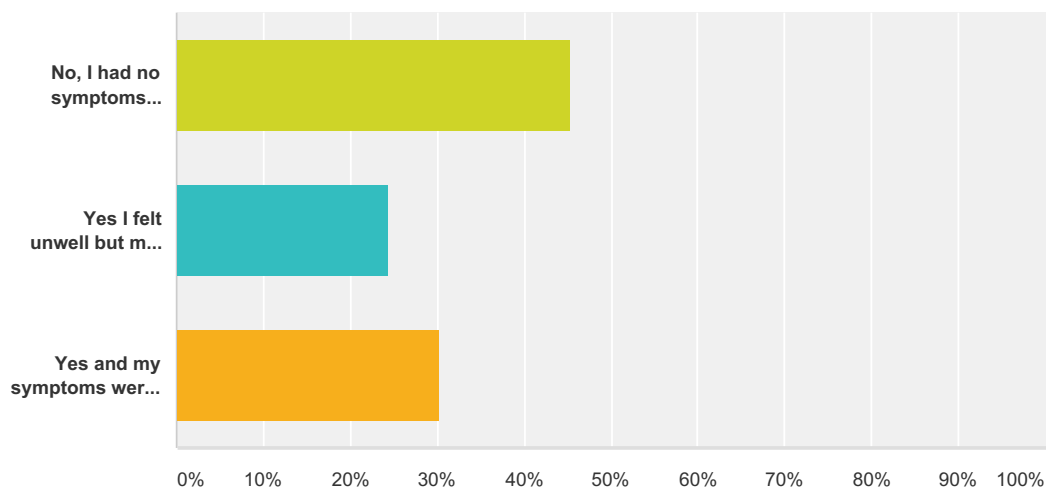
Answered: 106 Skipped: 5



Answer Choices	Responses
ultrasound scan	32.08% 34
MRI scan	6.60% 7
CT scan	49.06% 52
traditional x-ray	6.60% 7
percutaneous kidney biopsy (through your skin)	1.89% 2
I'm not sure which tests and scans I have recieved	0.94% 1
Other (please specify)	2.83% 3
Total	106

Q6 Did you feel unwell before being diagnosed with kidney cancer?

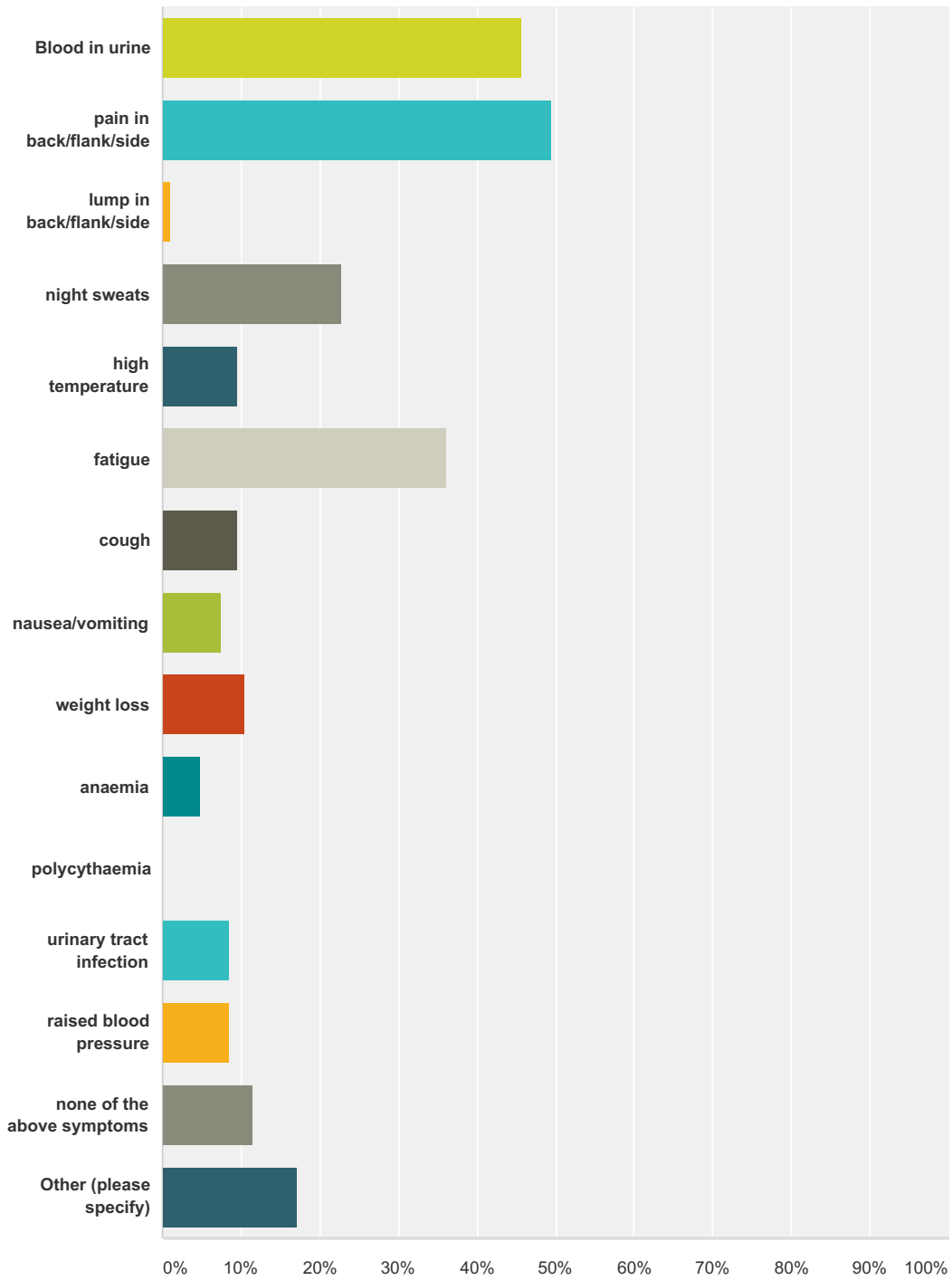
Answered: 106 Skipped: 5



Answer Choices	Responses	Count
No, I had no symptoms related to kidney cancer	45.28%	48
Yes I felt unwell but my symptoms were NOT related to kidney cancer	24.53%	26
Yes and my symptoms were related to kidney cancer	30.19%	32
Total		106

Q7 Which symptoms did you experience BEFORE being diagnosed with kidney cancer? (tick all that apply)

Answered: 105 Skipped: 6

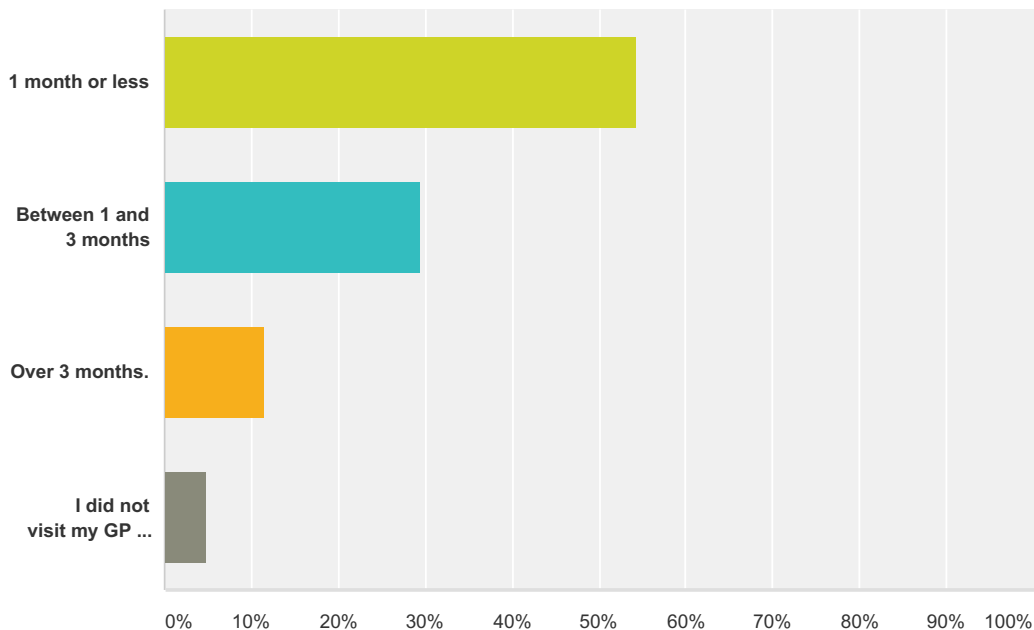


Answer Choices	Responses
Blood in urine	45.71% 48

pain in back/flank/side	49.52%	52
lump in back/flank/side	0.95%	1
night sweats	22.86%	24
high temperature	9.52%	10
fatigue	36.19%	38
cough	9.52%	10
nausea/vomiting	7.62%	8
weight loss	10.48%	11
anaemia	4.76%	5
polycythaemia	0.00%	0
urinary tract infection	8.57%	9
raised blood pressure	8.57%	9
none of the above symptoms	11.43%	12
Other (please specify)	17.14%	18
Total Respondents: 105		

Q8 If applicable, how long did it take from your first visit to the GP/ A&E to being diagnosed with kidney cancer?

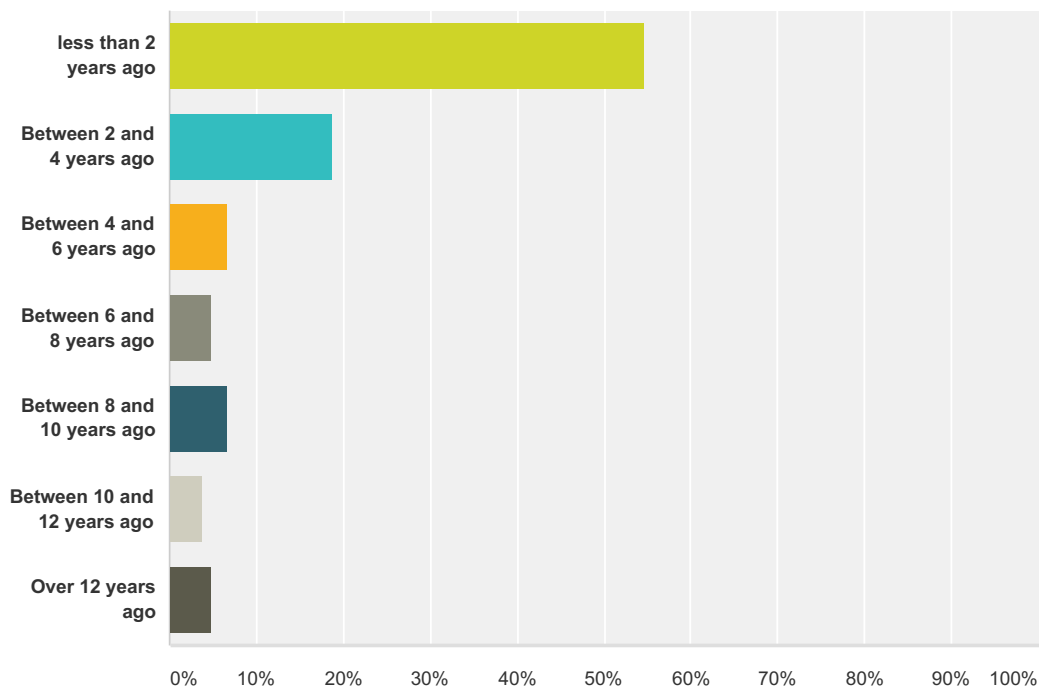
Answered: 105 Skipped: 6



Answer Choices	Responses
1 month or less	54.29% 57
Between 1 and 3 months	29.52% 31
Over 3 months.	11.43% 12
I did not visit my GP or A&E service before diagnosis	4.76% 5
Total	105

Q9 How long ago were you diagnosed with kidney cancer?

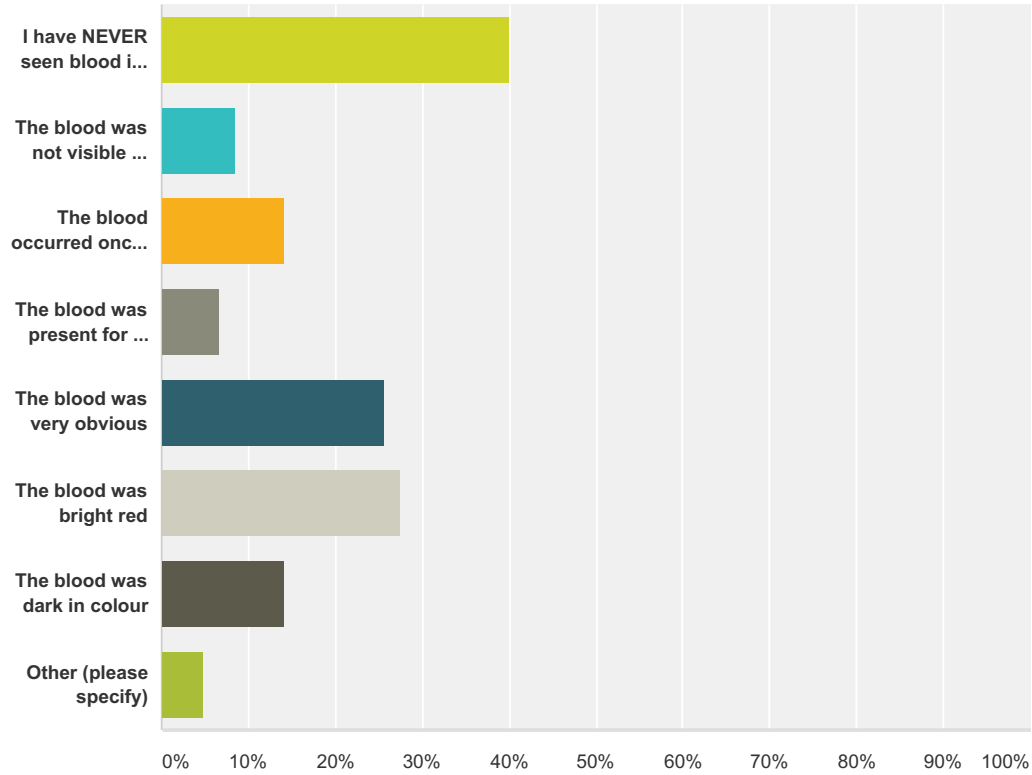
Answered: 106 Skipped: 5



Answer Choices	Responses	Count
less than 2 years ago	54.72%	58
Between 2 and 4 years ago	18.87%	20
Between 4 and 6 years ago	6.60%	7
Between 6 and 8 years ago	4.72%	5
Between 8 and 10 years ago	6.60%	7
Between 10 and 12 years ago	3.77%	4
Over 12 years ago	4.72%	5
Total		106

Q10 Have you ever seen blood in your urine (haematuria)? If so what best describes it? (tick all that apply)

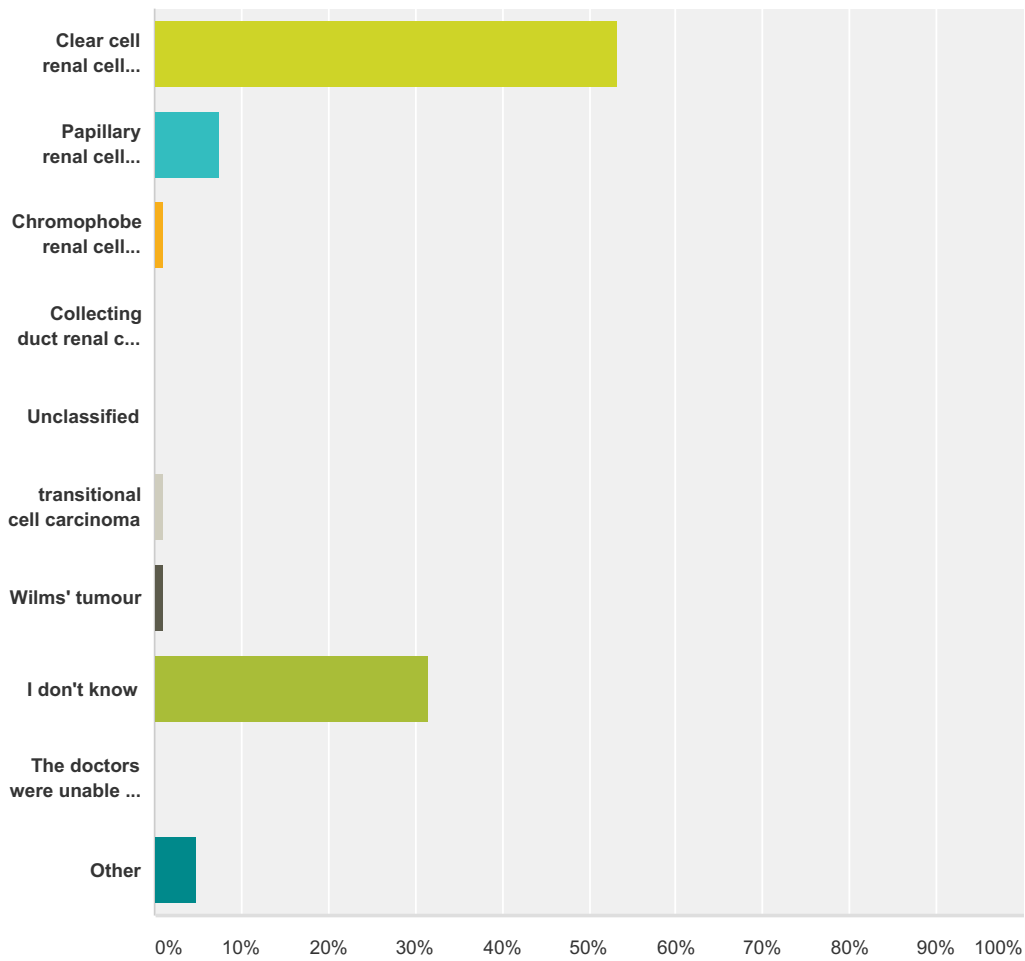
Answered: 105 Skipped: 6



Answer Choices	Responses
I have NEVER seen blood in my urine	40.00% 42
The blood was not visible but a urine test detected it	8.57% 9
The blood occurred once or twice but never again	14.29% 15
The blood was present for at least a week	6.67% 7
The blood was very obvious	25.71% 27
The blood was bright red	27.62% 29
The blood was dark in colour	14.29% 15
Other (please specify)	4.76% 5
Total Respondents: 105	

Q11 Do you know what type of kidney cancer you have been diagnosed with?

Answered: 105 Skipped: 6

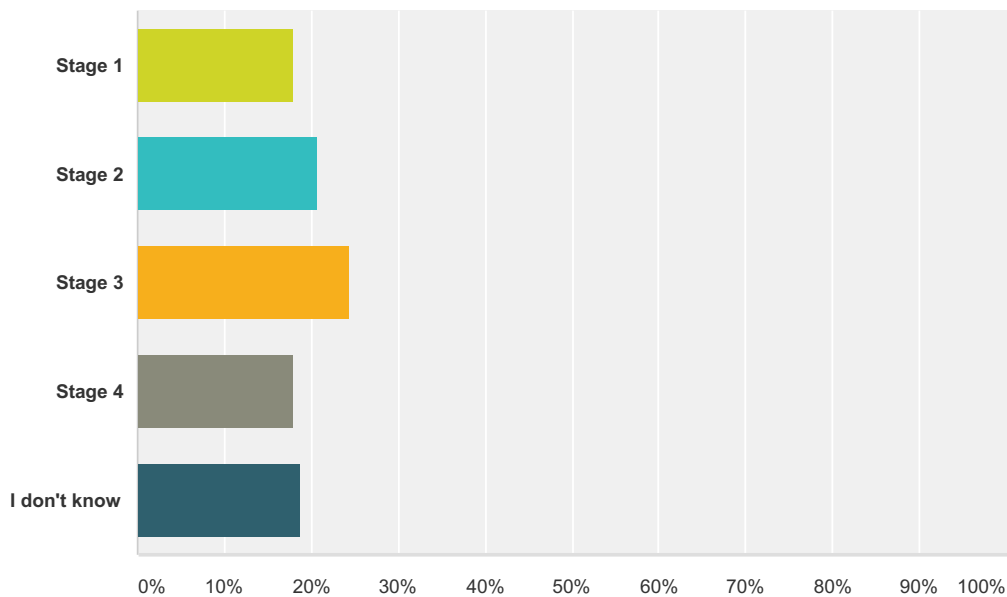


Answer Choices	Responses	Count
Clear cell renal cell carcinoma (non papillary)	53.33%	56
Papillary renal cell carcinoma	7.62%	8
Chromophobe renal cell carcinoma	0.95%	1
Collecting duct renal cell carcinoma	0.00%	0
Unclassified	0.00%	0
transitional cell carcinoma	0.95%	1
Wilms' tumour	0.95%	1
I don't know	31.43%	33
The doctors were unable to find out	0.00%	0
Other	4.76%	5

Total	105
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Q12 What stage was your cancer at diagnosis?

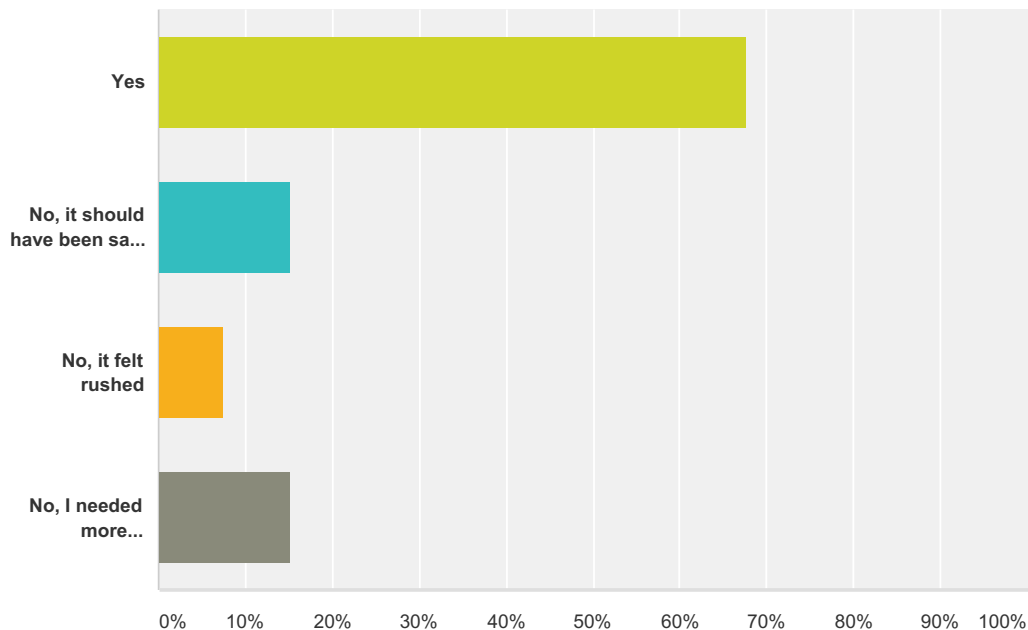
Answered: 106 Skipped: 5



Answer Choices	Responses
Stage 1	17.92% 19
Stage 2	20.75% 22
Stage 3	24.53% 26
Stage 4	17.92% 19
I don't know	18.87% 20
Total	106

Q13 Was the way in which you were told about having kidney cancer appropriate? (tick all that apply)

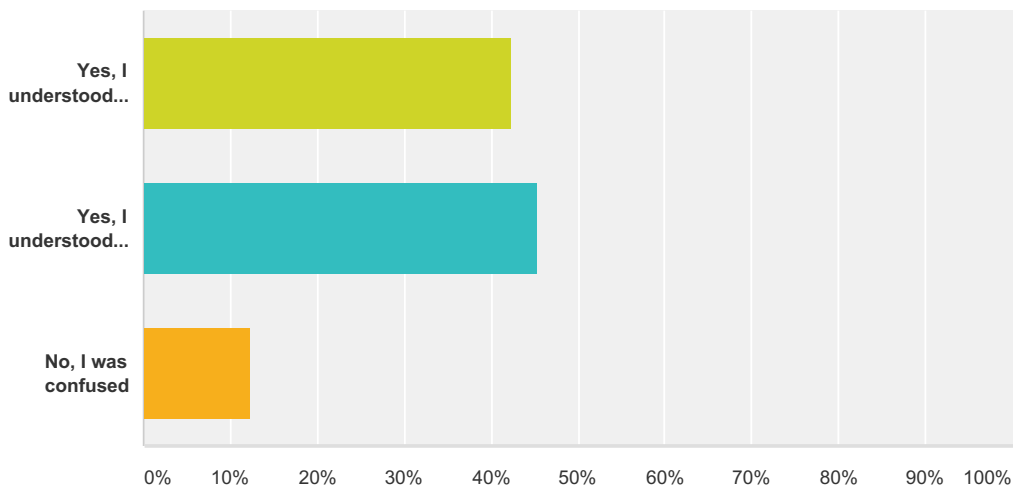
Answered: 105 Skipped: 6



Answer Choices	Responses
Yes	67.62% 71
No, it should have been said in a more sensitive way	15.24% 16
No, it felt rushed	7.62% 8
No, I needed more information	15.24% 16
Total Respondents: 105	

Q14 Were you told you had cancer in a way that was easily understood?

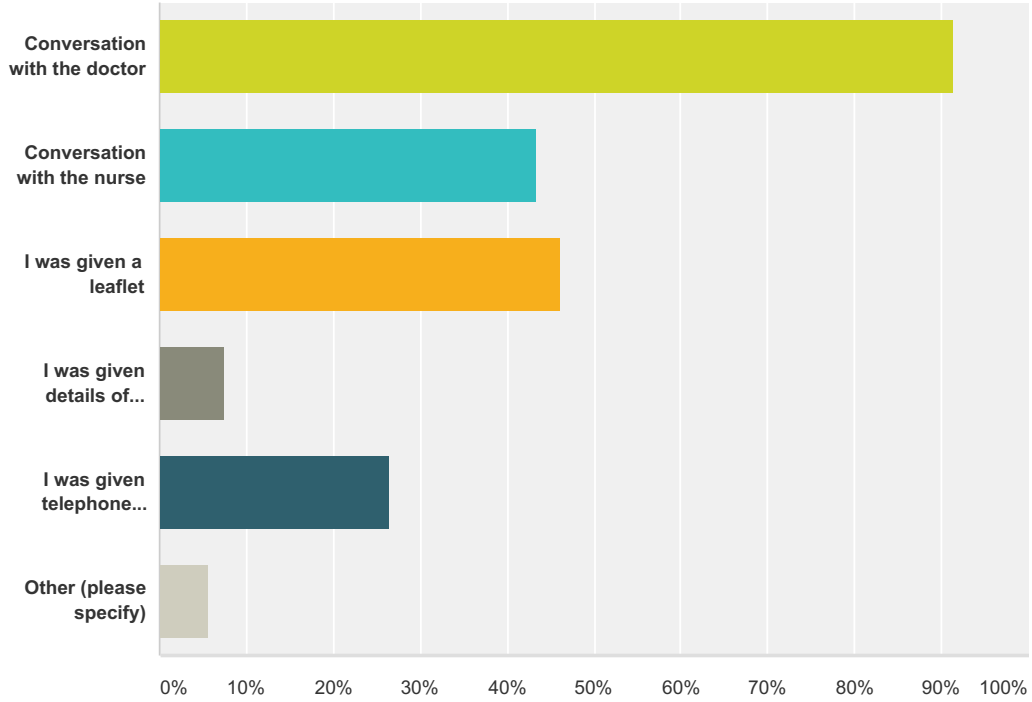
Answered: 106 Skipped: 5



Answer Choices	Responses
Yes, I understood everything and didn't want any more information	42.45% 45
Yes, I understood everything but still wanted more information	45.28% 48
No, I was confused	12.26% 13
Total Respondents: 106	

Q15 What type of information did you receive at the hospital clinic? (tick all that apply)

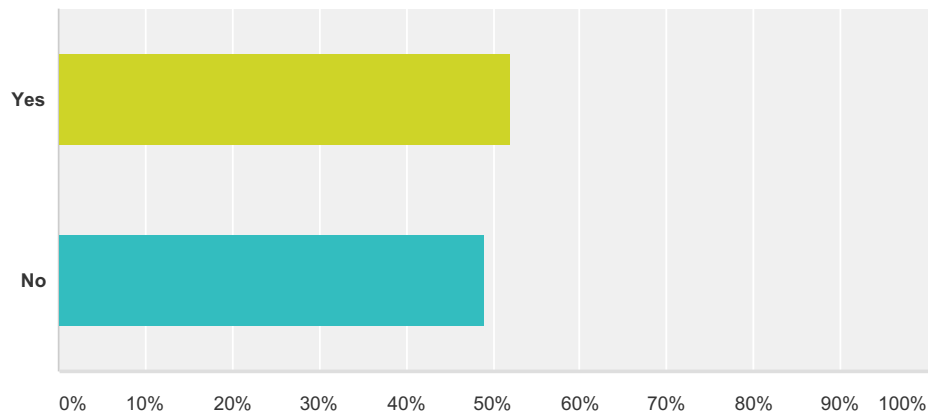
Answered: 106 Skipped: 5



Answer Choices	Responses
Conversation with the doctor	91.51% 97
Conversation with the nurse	43.40% 46
I was given a leaflet	46.23% 49
I was given details of websites to view	7.55% 8
I was given telephone numbers to call for more support and information	26.42% 28
Other (please specify)	5.66% 6
Total Respondents: 106	

Q16 Did you recieve enough information about kidney cancer?

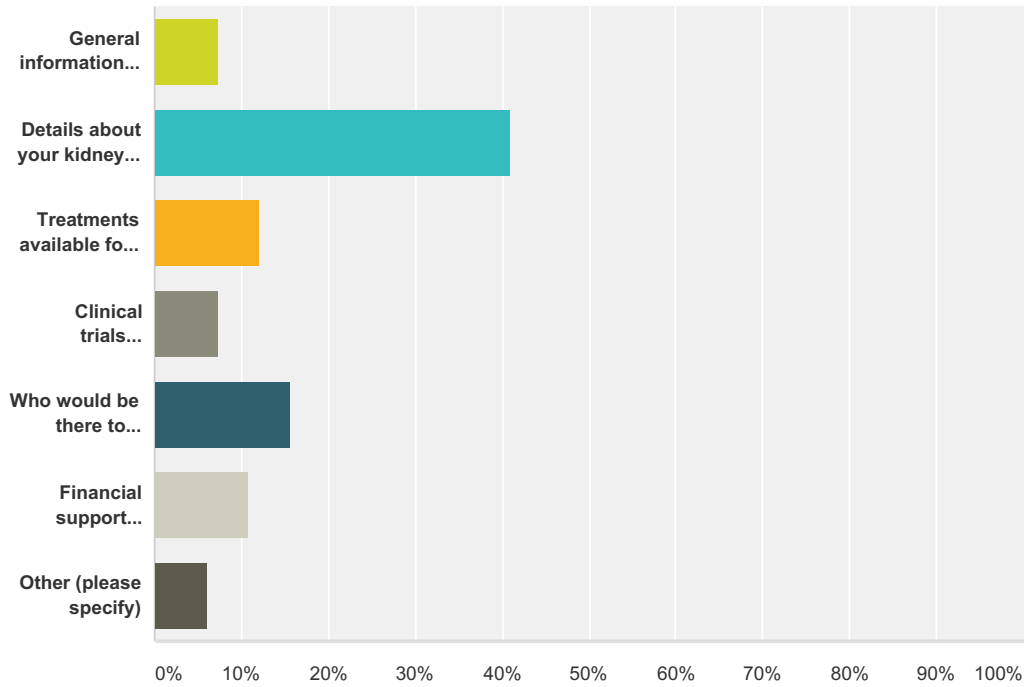
Answered: 106 Skipped: 5



Answer Choices	Responses	
Yes	51.89%	55
No	49.06%	52
Total Respondents: 106		

Q17 If you would have liked more information when you were diagnosed, what would you have liked to have known more about?

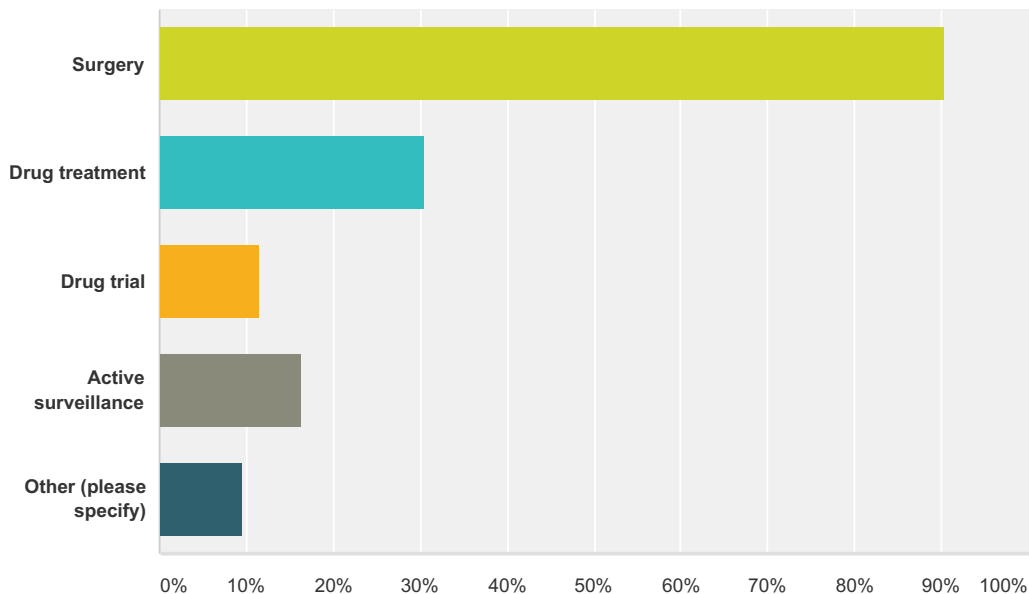
Answered: 83 Skipped: 28



Answer Choices	Responses
General information about kidney cancer	7.23% 6
Details about your kidney cancer stage, type and what this means	40.96% 34
Treatments available for me	12.05% 10
Clinical trials available to me	7.23% 6
Who would be there to support me (nurses, charities, carelines, support networks)	15.66% 13
Financial support information	10.84% 9
Other (please specify)	6.02% 5
Total	83

Q18 What type of treatment have you received or are due to have for kidney cancer? (tick all that apply)

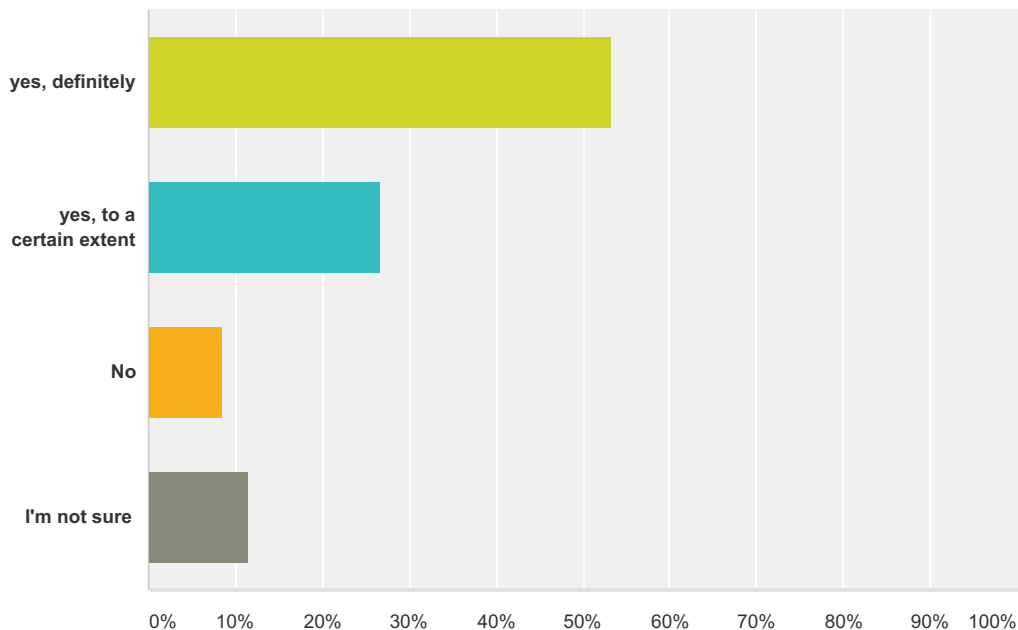
Answered: 105 Skipped: 6



Answer Choices	Responses	Count
Surgery	90.48%	95
Drug treatment	30.48%	32
Drug trial	11.43%	12
Active surveillance	16.19%	17
Other (please specify)	9.52%	10
Total Respondents: 105		

Q19 Do you think your views were taken into account when the team of doctors and nurses were deciding your future care?

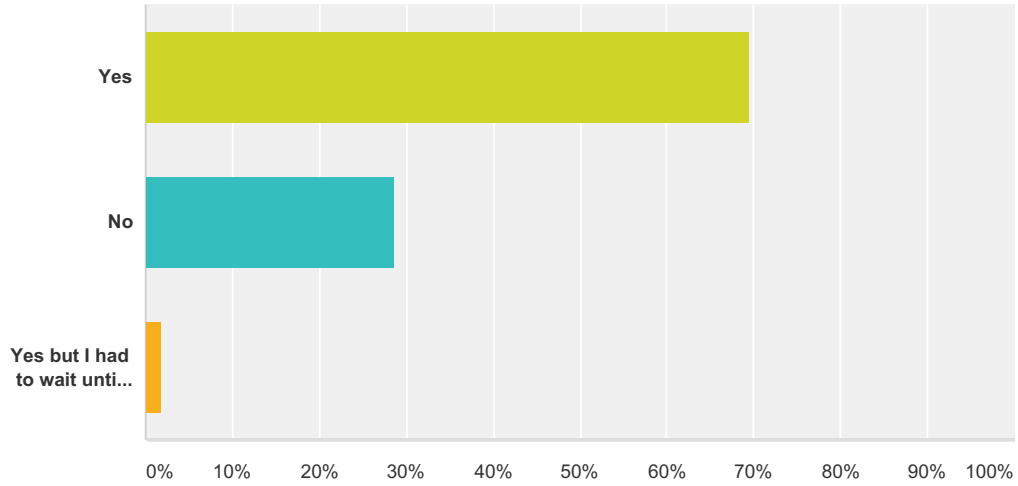
Answered: 105 Skipped: 6



Answer Choices	Responses
yes, definitely	53.33% 56
yes, to a certain extent	26.67% 28
No	8.57% 9
I'm not sure	11.43% 12
Total	105

Q20 Were you given the name of a Clinical Nurse Specialist (CNS) who would be in charge of your care?

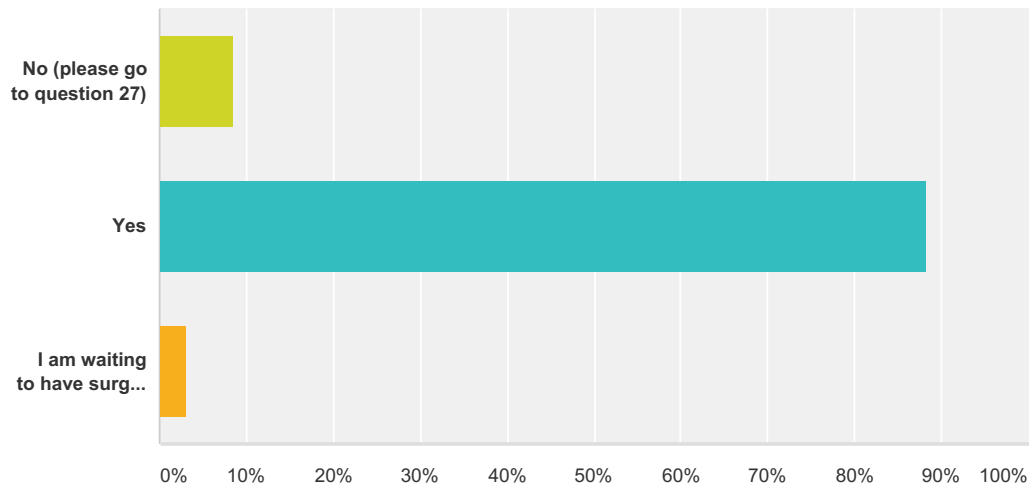
Answered: 105 Skipped: 6



Answer Choices	Responses
Yes	69.52% 73
No	28.57% 30
Yes but I had to wait until one was available	1.90% 2
Total	105

Q21 Have you had surgery for kidney cancer?

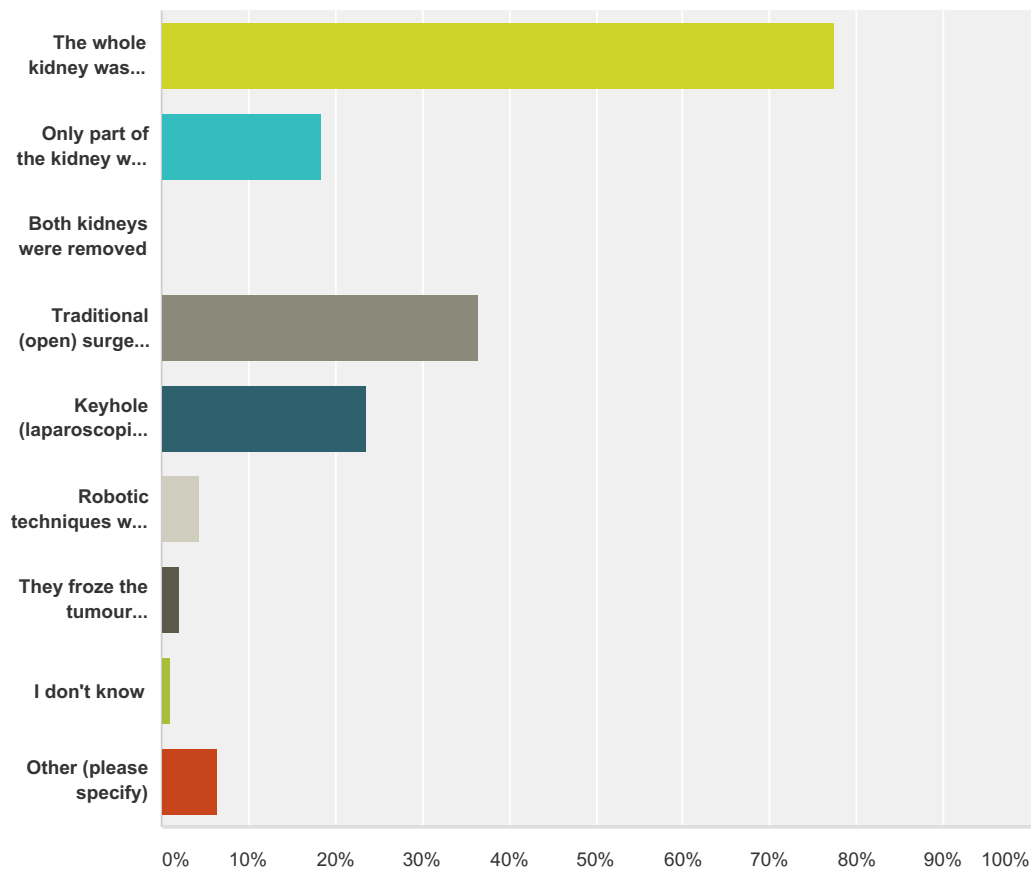
Answered: 94 Skipped: 17



Answer Choices	Responses
No (please go to question 27)	8.51% 8
Yes	88.30% 83
I am waiting to have surgery in the near future.	3.19% 3
Total	94

Q22 What type of surgery have you received or are due to have? (tick all that apply)

Answered: 93 Skipped: 18



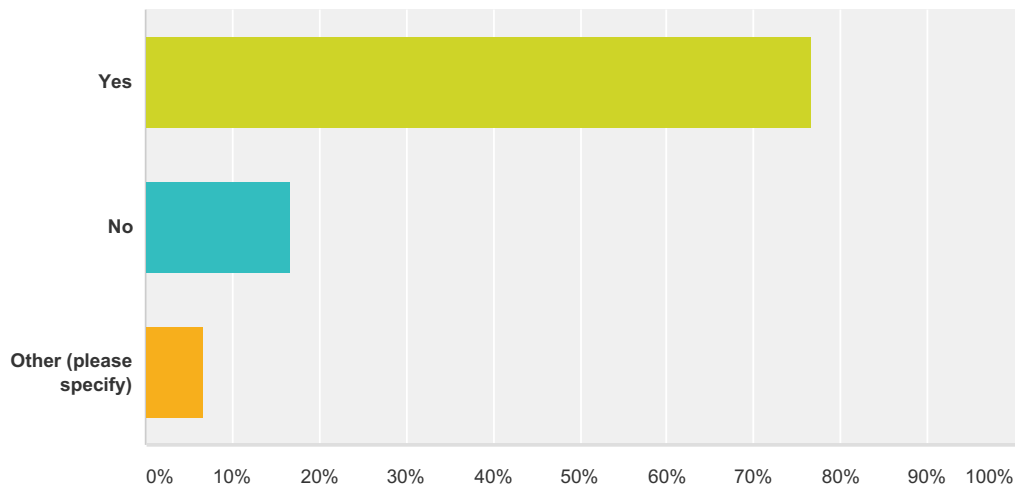
Answer Choices	Responses
The whole kidney was removed	77.42% 72
Only part of the kidney was removed	18.28% 17
Both kidneys were removed	0.00% 0
Traditional (open) surgery was used	36.56% 34
Keyhole (laparoscopic) surgery was used	23.66% 22
Robotic techniques were used	4.30% 4
They froze the tumour (cryoablation)	2.15% 2
I don't know	1.08% 1
Other (please specify)	6.45% 6
Total Respondents: 93	

Q23 At which hospital did you have your surgery?

Answered: 93 Skipped: 18

Q24 Were you happy with the information and support you received before and after your surgery?

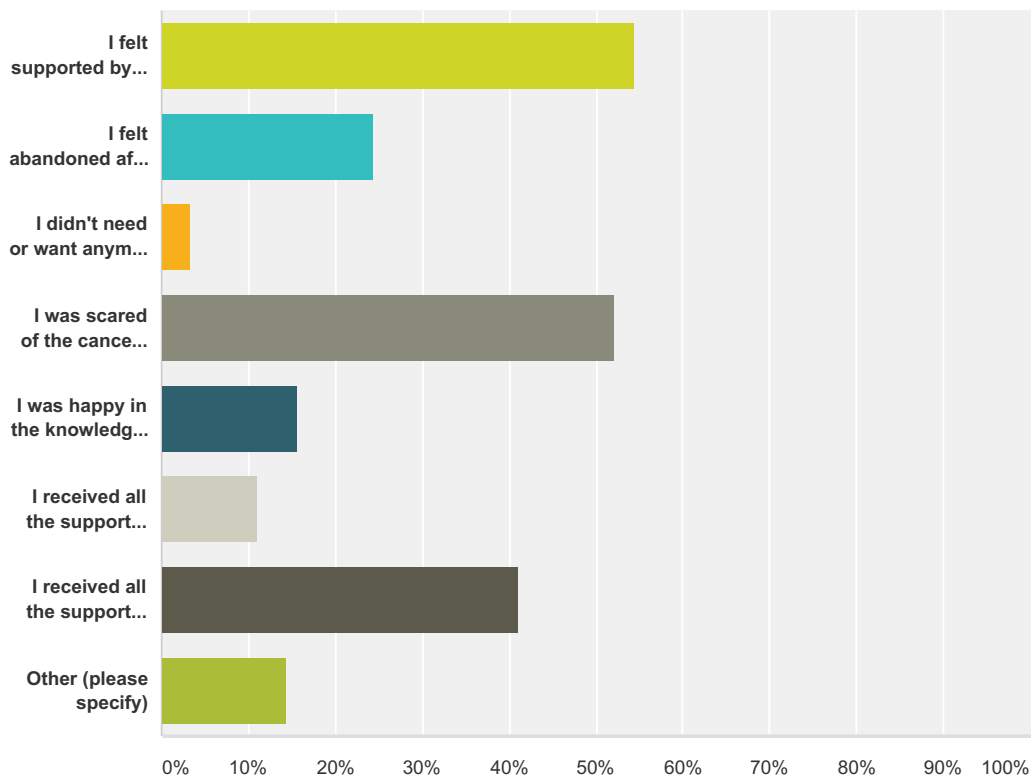
Answered: 90 Skipped: 21



Answer Choices	Responses	Count
Yes	76.67%	69
No	16.67%	15
Other (please specify)	6.67%	6
Total		90

Q25 Which statements describe how you felt after surgery? (tick all that apply)

Answered: 90 Skipped: 21



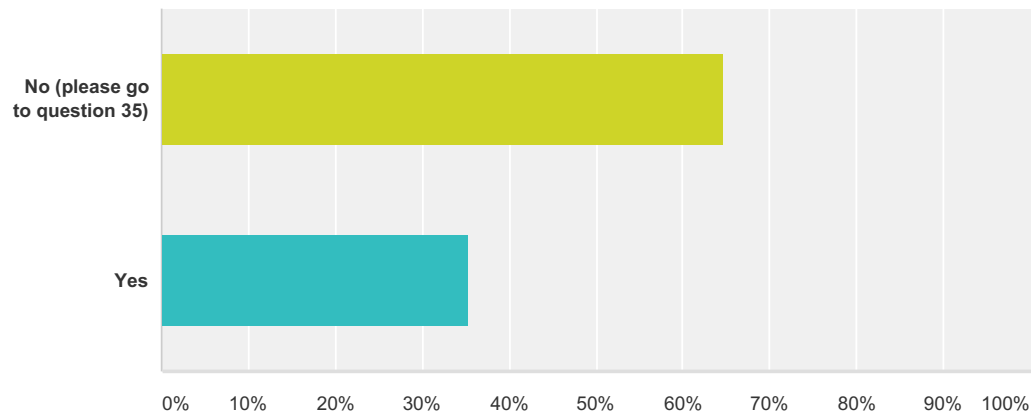
Answer Choices	Responses
I felt supported by the health professionals looking after me	54.44% 49
I felt abandoned after surgery and wished there was more contact with health professionals	24.44% 22
I didn't need or want anymore support after surgery	3.33% 3
I was scared of the cancer reoccurring	52.22% 47
I was happy in the knowledge that the cancer had been removed and didn't want to think about it any more	15.56% 14
I received all the support required from cancer charities	11.11% 10
I received all the support required from friends and family	41.11% 37
Other (please specify)	14.44% 13
Total Respondents: 90	

Q26 If you were unhappy with the support received after surgery, please let us know what type of support would have been useful?

Answered: 23 Skipped: 88

Q27 Have you received drug treatment for kidney cancer?

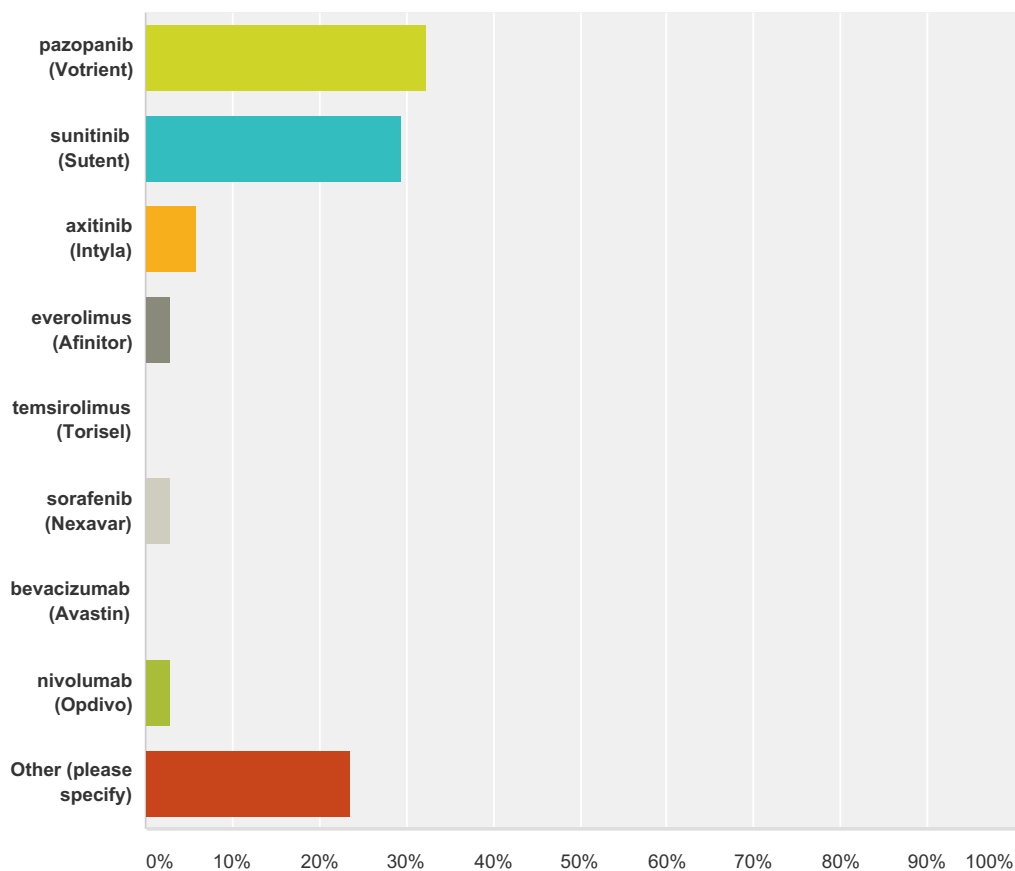
Answered: 99 Skipped: 12



Answer Choices	Responses	
No (please go to question 35)	64.65%	64
Yes	35.35%	35
Total		99

Q28 Which medicines have you taken for kidney cancer?

Answered: 34 Skipped: 77



Answer Choices	Responses
pazopanib (Votrient)	32.35% 11
sunitinib (Sutent)	29.41% 10
axitinib (Intyla)	5.88% 2
everolimus (Afinitor)	2.94% 1
temsirolimus (Torisel)	0.00% 0
sorafenib (Nexavar)	2.94% 1
bevacizumab (Avastin)	0.00% 0
nivolumab (Opdivo)	2.94% 1
Other (please specify)	23.53% 8
Total	34

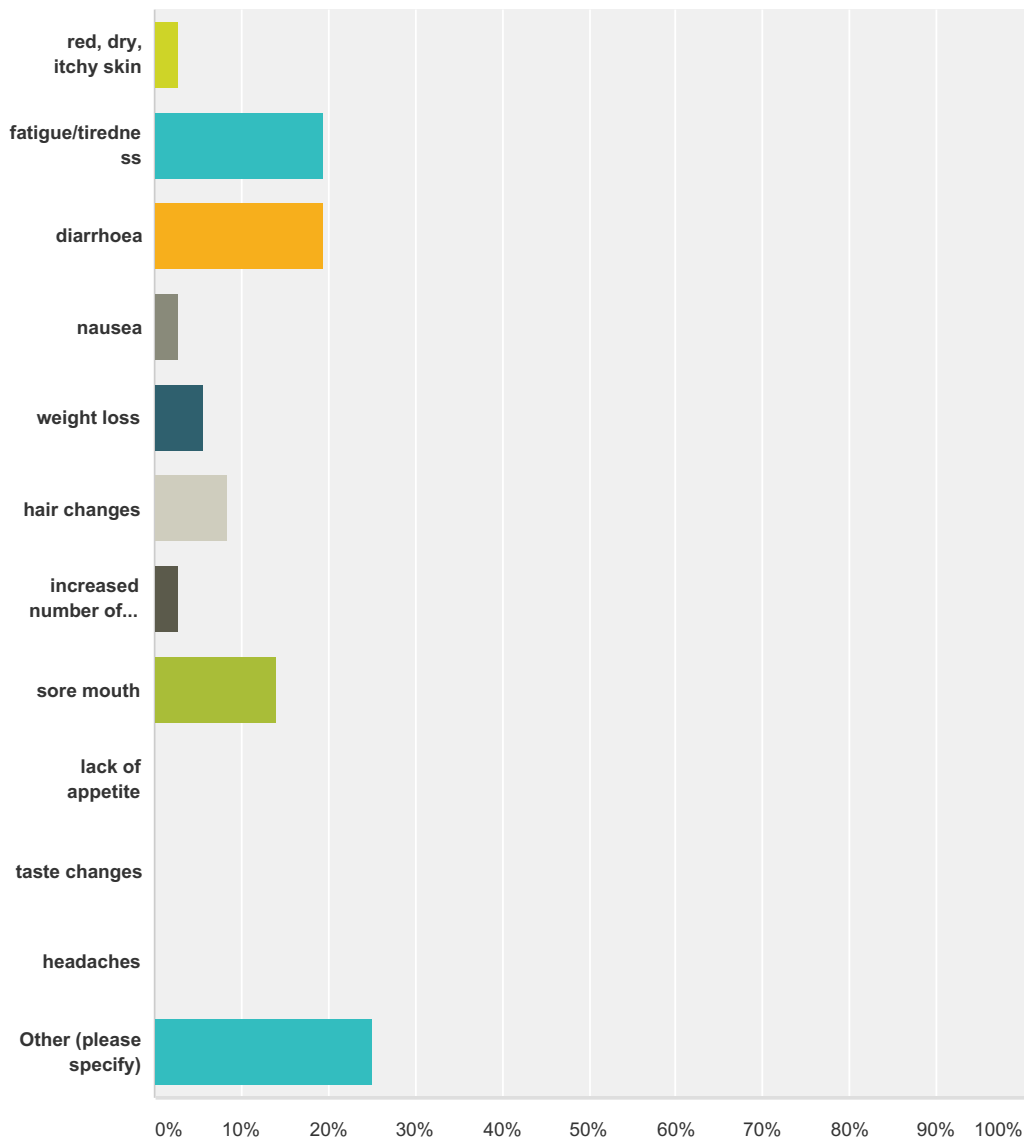
Q29 If you have had more than one treatment please tell us which drugs were your 1st, 2nd and 3rd line treatments.

Answered: 15 Skipped: 96

Answer Choices	Responses	
1st line treatment	100.00%	15
2nd line treatment	80.00%	12
3rd line treatment	46.67%	7

Q30 Which side-effects have you experienced? Please tick the most distressing side effect.

Answered: 36 Skipped: 75

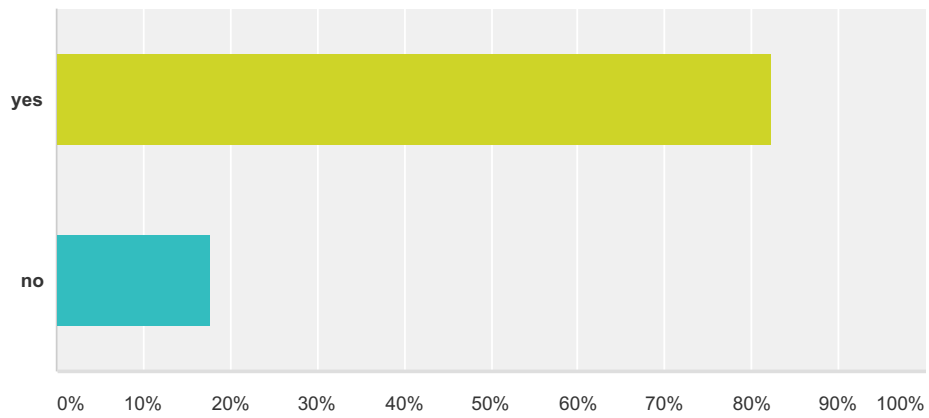


Answer Choices	Responses
red, dry, itchy skin	2.78% 1
fatigue/tiredness	19.44% 7
diarrhoea	19.44% 7
nausea	2.78% 1
weight loss	5.56% 2
hair changes	8.33% 3

increased number of infections	2.78%	1
sore mouth	13.89%	5
lack of appetite	0.00%	0
taste changes	0.00%	0
headaches	0.00%	0
Other (please specify)	25.00%	9
Total		36

Q31 Were you given enough support and information on side effects?

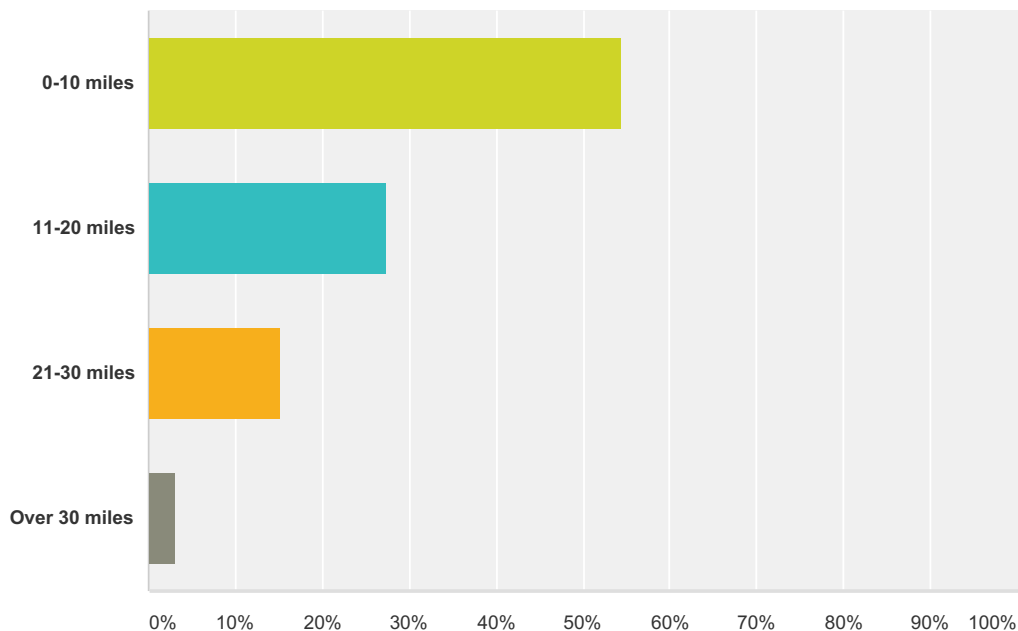
Answered: 34 Skipped: 77



Answer Choices	Responses	
yes	82.35%	28
no	17.65%	6
Total		34

Q32 How far did you have to travel for drug treatment?

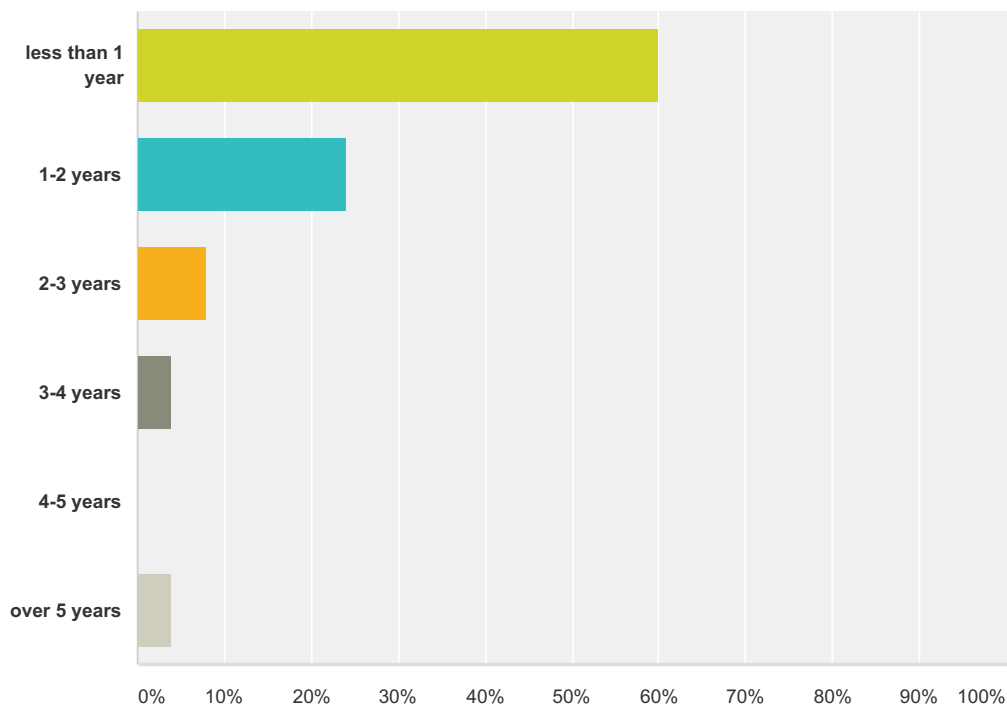
Answered: 33 Skipped: 78



Answer Choices	Responses
0-10 miles	54.55% 18
11-20 miles	27.27% 9
21-30 miles	15.15% 5
Over 30 miles	3.03% 1
Total	33

Q33 How long were you on your drug treatment for? (Please provide details of 2nd or 3rd line treatments in the 'other' box below)

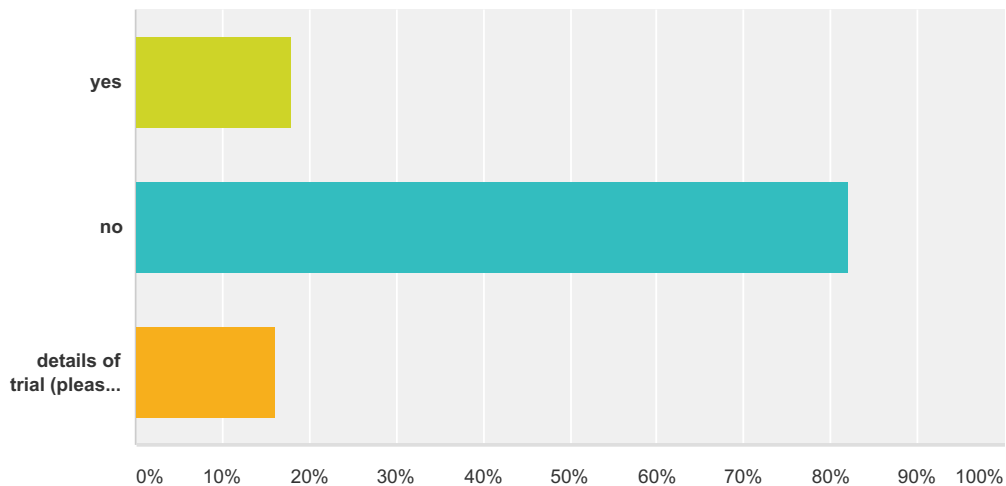
Answered: 25 Skipped: 86



Answer Choices	Responses	Count
less than 1 year	60.00%	15
1-2 years	24.00%	6
2-3 years	8.00%	2
3-4 years	4.00%	1
4-5 years	0.00%	0
over 5 years	4.00%	1
Total		25

Q34 Have you ever been involved in a kidney cancer clinical trial? Please provide trial name if applicable.

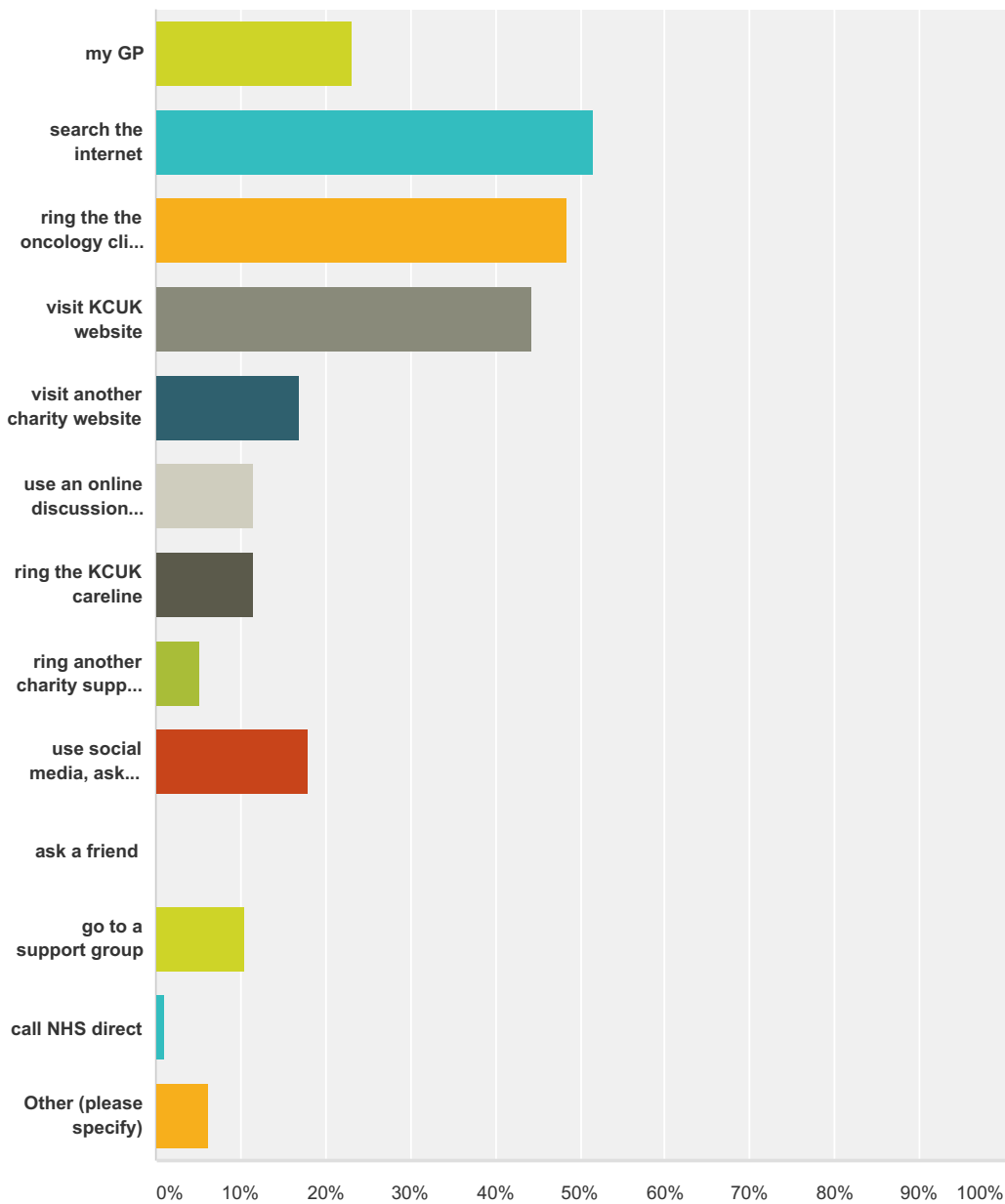
Answered: 56 Skipped: 55



Answer Choices	Responses
yes	17.86% 10
no	82.14% 46
details of trial (please specify)	16.07% 9
Total Respondents: 56	

Q35 If you wanted support or information about kidney cancer where would you turn first?

Answered: 95 Skipped: 16

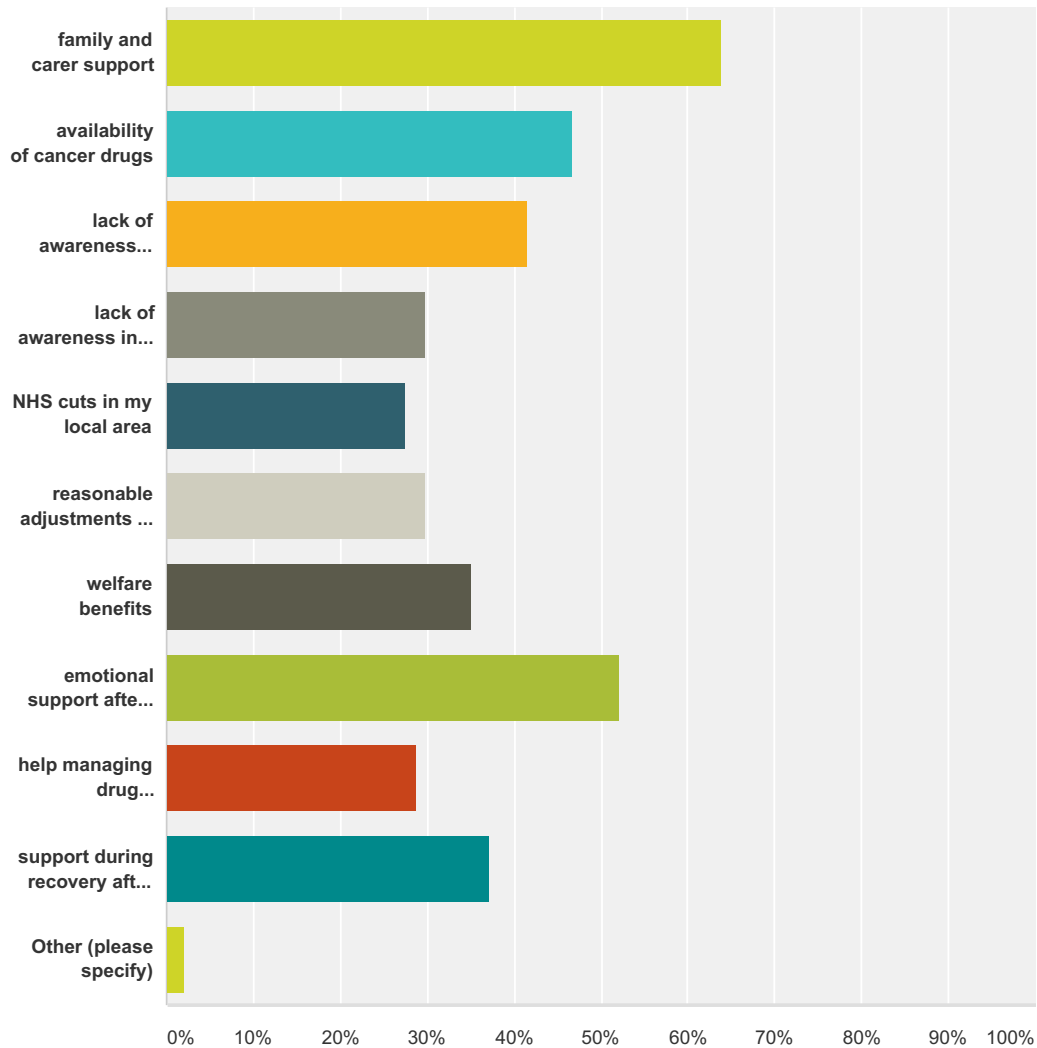


Answer Choices	Responses
my GP	23.16% 22
search the internet	51.58% 49
ring the the oncology clinic or my named clinical nurse specialist	48.42% 46
visit KCUK website	44.21% 42
visit another charity website	16.84% 16

use an online discussion forum	11.58%	11
ring the KCUK careline	11.58%	11
ring another charity support line	5.26%	5
use social media, ask questions on a facebook group	17.89%	17
ask a friend	0.00%	0
go to a support group	10.53%	10
call NHS direct	1.05%	1
Other (please specify)	6.32%	6
Total Respondents: 95		

Q36 Which of the following issues do you think could have an impact on people living with kidney cancer?

Answered: 94 Skipped: 17

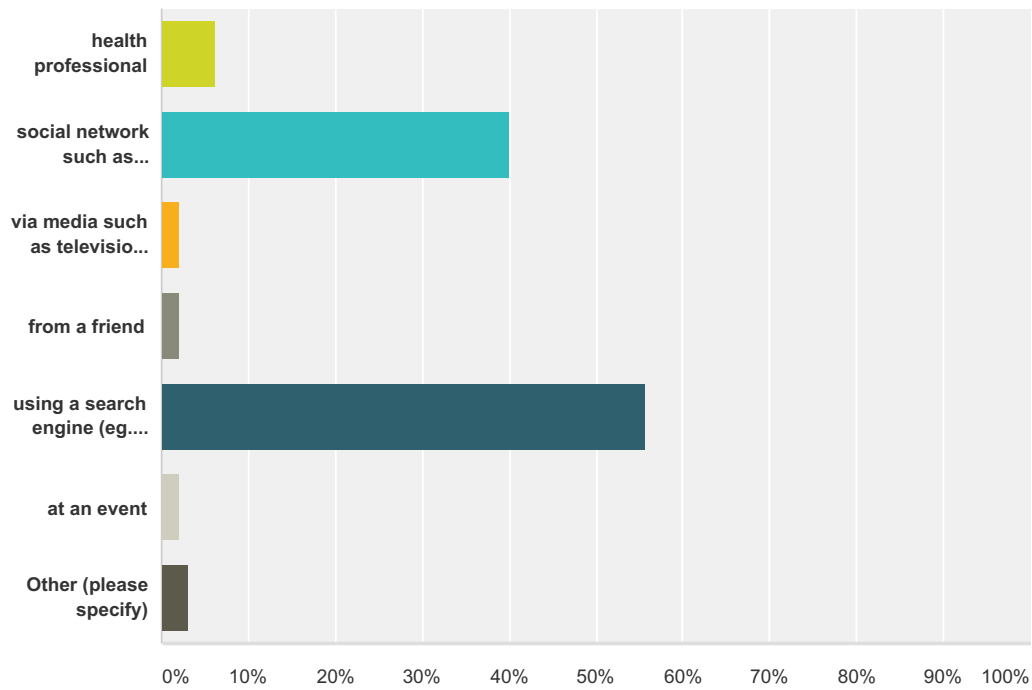


Answer Choices	Responses
family and carer support	63.83% 60
availability of cancer drugs	46.81% 44
lack of awareness amongst the public	41.49% 39
lack of awareness in primary care (e.g GP's)	29.79% 28
NHS cuts in my local area	27.66% 26
reasonable adjustments at work	29.79% 28
welfare benefits	35.11% 33
emotional support after cancer	52.13% 49

help managing drug side-effects	28.72%	27
support during recovery after surgery	37.23%	35
Other (please specify)	2.13%	2
Total Respondents: 94		

Q37 How did you find out about Kidney Cancer UK?

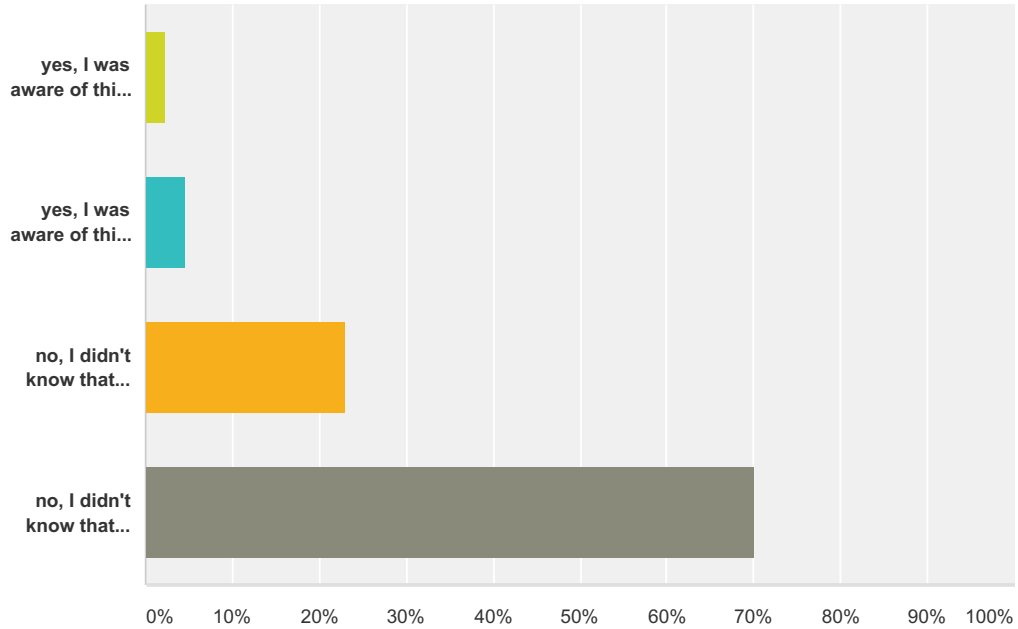
Answered: 95 Skipped: 16



Answer Choices	Responses
health professional	6.32% 6
social network such as facebook	40.00% 38
via media such as television or newspaper	2.11% 2
from a friend	2.11% 2
using a search engine (eg. google)	55.79% 53
at an event	2.11% 2
Other (please specify)	3.16% 3
Total Respondents: 95	

Q38 Are you aware that Kidney Cancer UK offers grants for people who wish to set up support group in their local area?

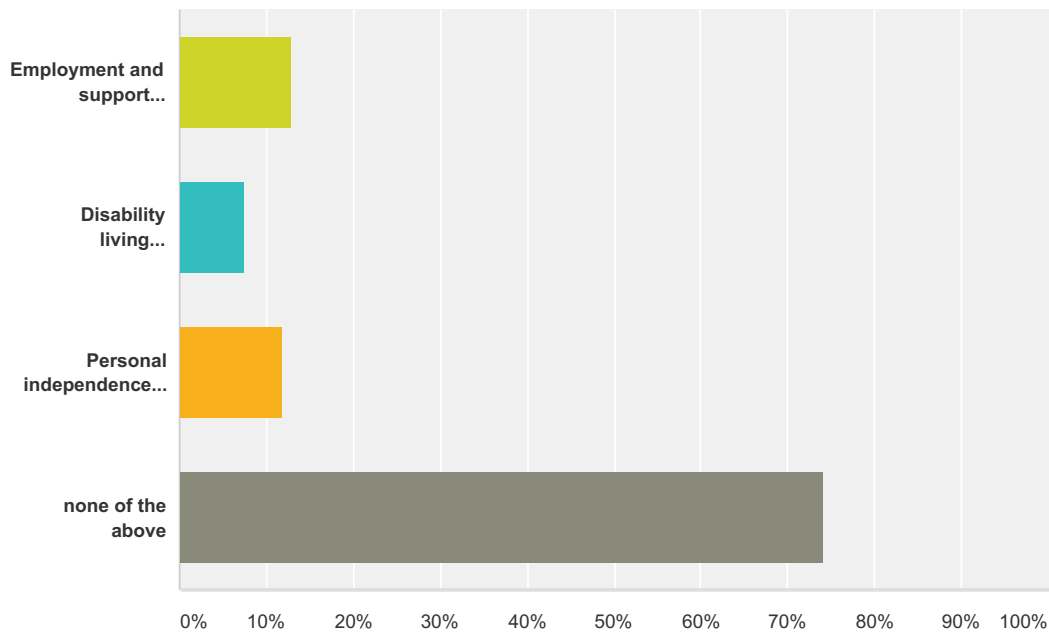
Answered: 87 Skipped: 24



Answer Choices	Responses
yes, I was aware of this and I would be interested in helping set up a support group in my area.	2.30% 2
yes, I was aware of this but I would NOT be interested in helping set up a support group in my area.	4.60% 4
no, I didn't know that grants were available but I would be interested in helping set up a support group in my area	22.99% 20
no, I didn't know that grants were available and I would NOT be interested in helping set up a support group in my area	70.11% 61
Total	87

Q39 As a result of having kidney cancer have you received any of the following welfare benefits?

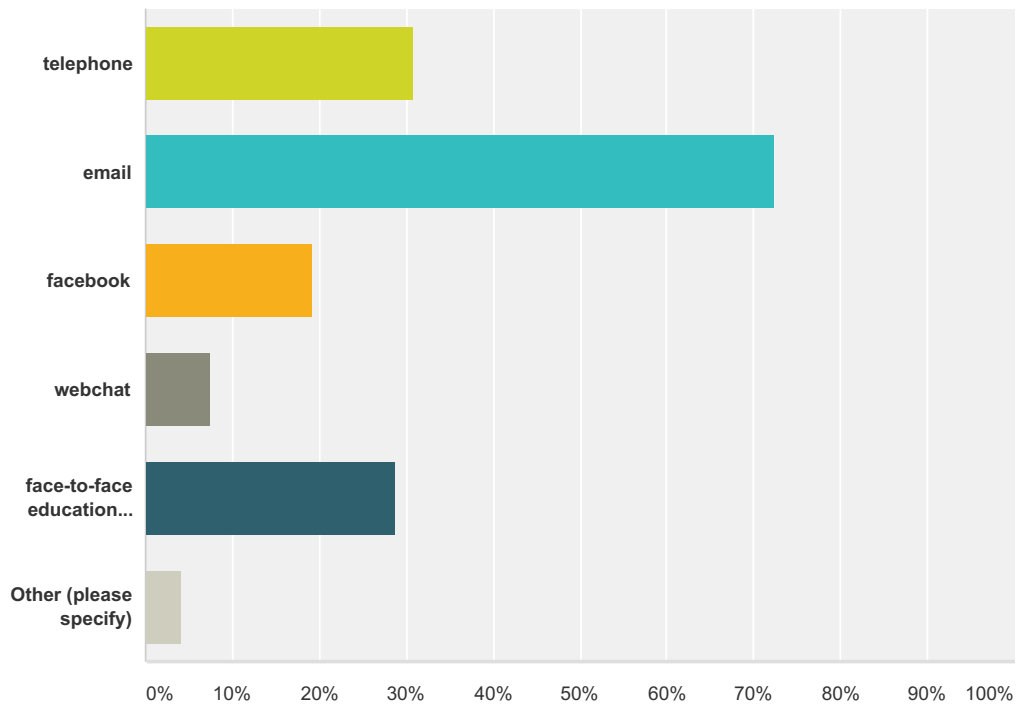
Answered: 93 Skipped: 18



Answer Choices	Responses
Employment and support allowance (ESA)	12.90% 12
Disability living allowance (DLA)	7.53% 7
Personal independence payment (PIP)	11.83% 11
none of the above	74.19% 69
Total Respondents: 93	

Q40 If you wanted information or support, how would you prefer to access it?

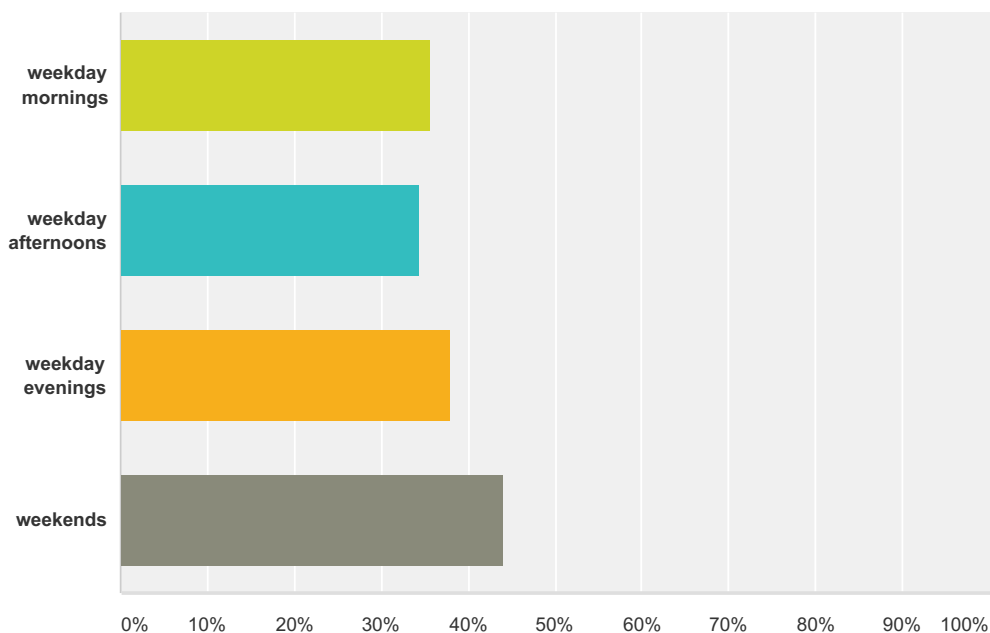
Answered: 94 Skipped: 17



Answer Choices	Responses	Count
telephone	30.85%	29
email	72.34%	68
facebook	19.15%	18
webchat	7.45%	7
face-to-face education sessions	28.72%	27
Other (please specify)	4.26%	4
Total Respondents: 94		

Q41 When would you like to access this support?

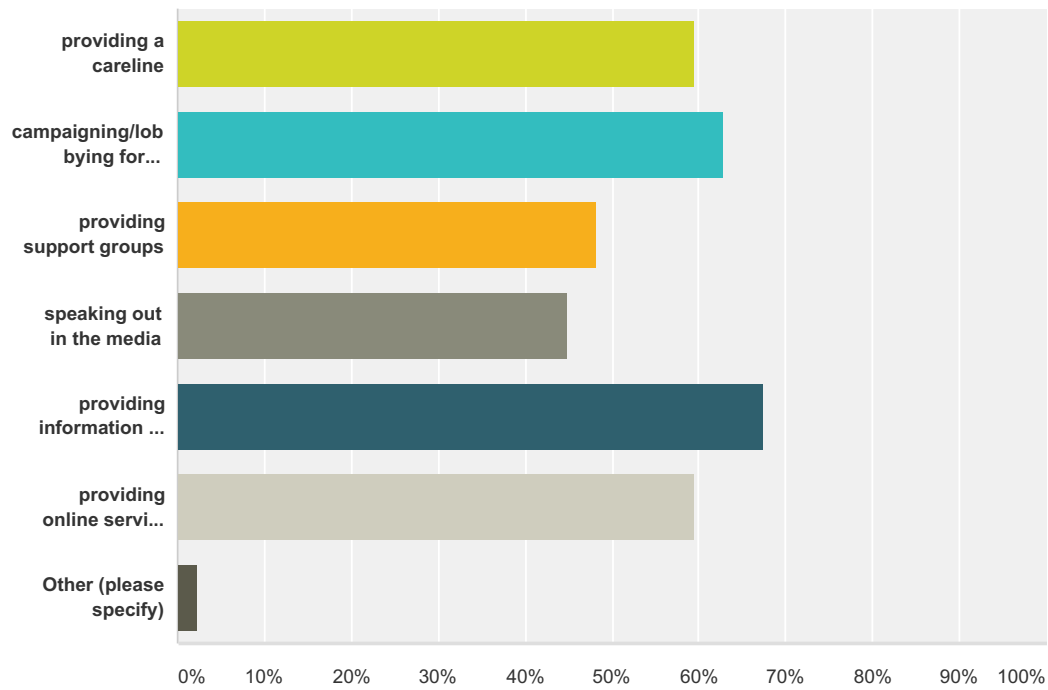
Answered: 84 Skipped: 27



Answer Choices	Responses
weekday mornings	35.71% 30
weekday afternoons	34.52% 29
weekday evenings	38.10% 32
weekends	44.05% 37
Total Respondents: 84	

Q42 Which aspects of Kidney Cancer UK's work are you aware of?

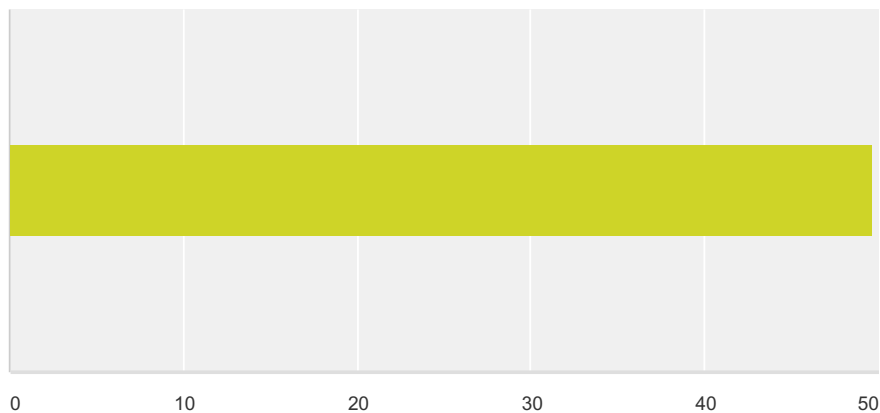
Answered: 89 Skipped: 22



Answer Choices	Responses
providing a careline	59.55% 53
campaigning/lobbying for improvements in kidney cancer care	62.92% 56
providing support groups	48.31% 43
speaking out in the media	44.94% 40
providing information on our website and factsheets	67.42% 60
providing online services such as our facebook group and forum	59.55% 53
Other (please specify)	2.25% 2
Total Respondents: 89	

Q43 Overall how satisfied are you with your kidney cancer care by rating it on a scale of 1 to 4? 1= dissatisfied 2= somewhat satisfied 3= satisfied 4= very satisfied

Answered: 94 Skipped: 17



Answer Choices	Average Number	Total Number	Responses
	50	4,673	94
Total Respondents: 94			

Q44 Please provide your email address if you would like to be added to our database for future information. All information provided in this survey is kept confidential. Thank you for completing this survey.

Answered: 60 Skipped: 51