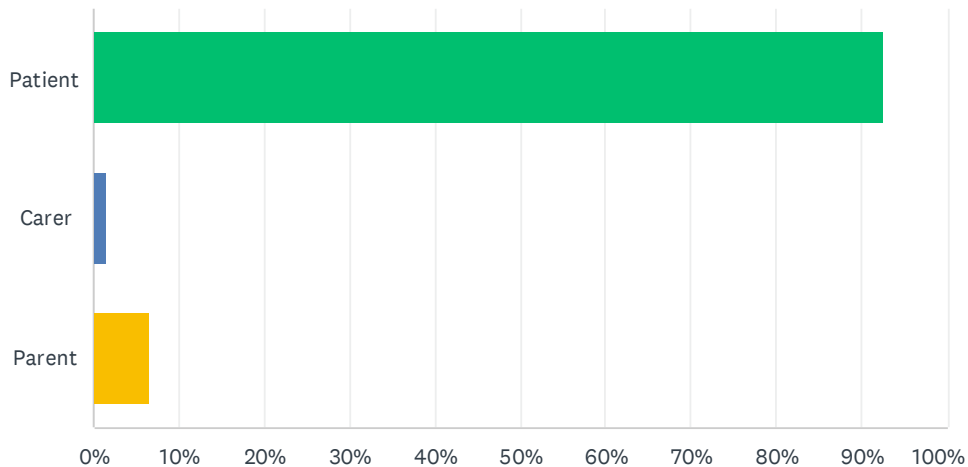


Q1 Are you completing this survey as an ITP patient, carer or the parent of a child with ITP? (Patient / Parent of a Child)

Answered: 134 Skipped: 0



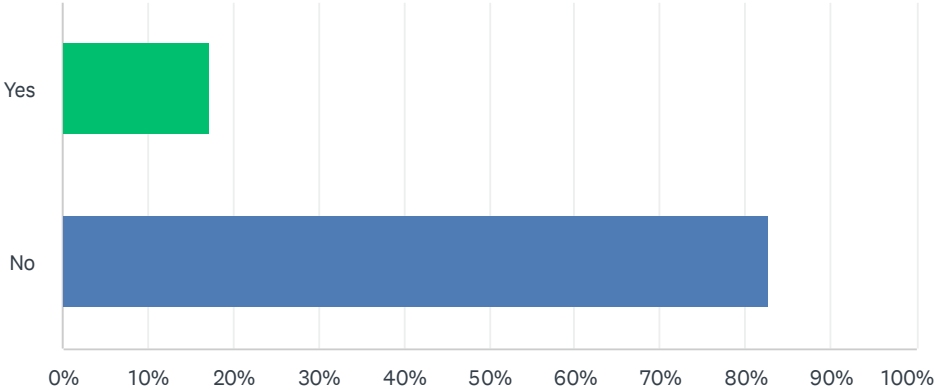
ANSWER CHOICES	RESPONSES	
Patient	92.54%	124
Carer	1.49%	2
Parent	6.72%	9
Total Respondents: 134		

Q2 Your Hospital or ITP Specialist Centre Name:

Answered: 134 Skipped: 0

Q3 Did you specifically ask to be referred to this Hospital or Specialist Centre (Yes / No)

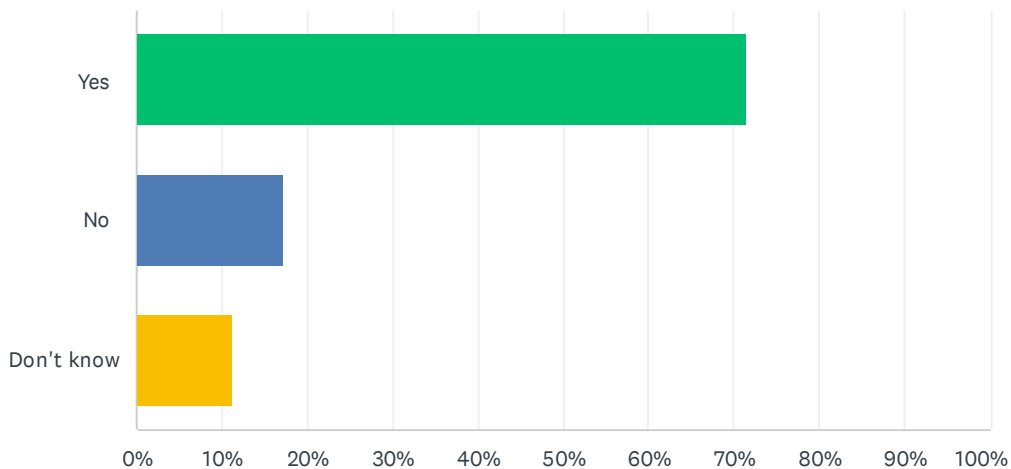
Answered: 133 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	17.29%	23
No	82.71%	110
Total Respondents: 133		

Q4 Does your doctor have a treatment plan for you? (Yes / No / Don't know)

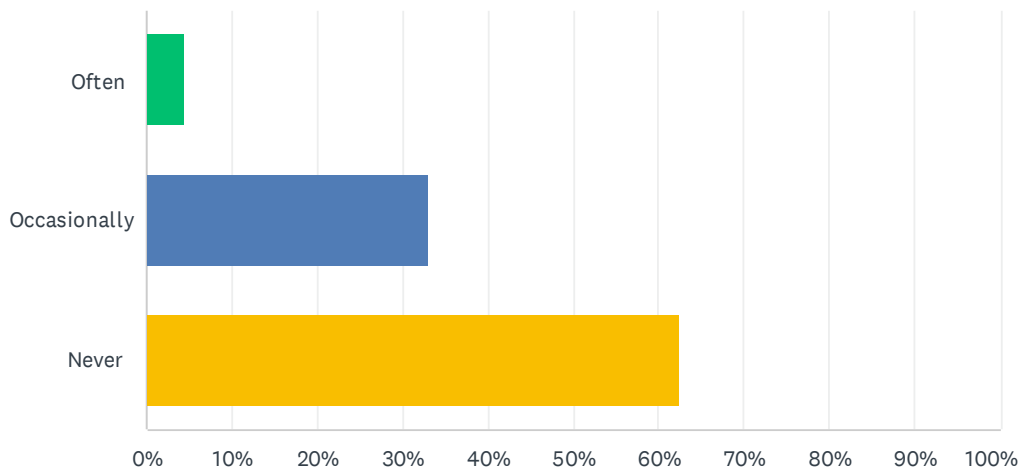
Answered: 133 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	71.43%	95
No	17.29%	23
Don't know	11.28%	15
Total Respondents: 133		

Q5 Have you ever had conflicting advice from different doctors in the team? (Often / Occasionally / Never)

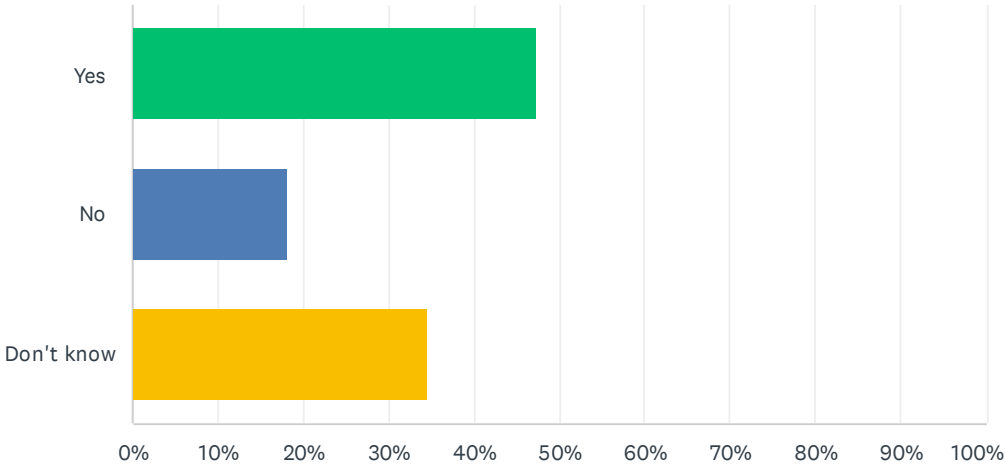
Answered: 133 Skipped: 1



ANSWER CHOICES	RESPONSES	
Often	4.51%	6
Occasionally	33.08%	44
Never	62.41%	83
Total Respondents: 133		

Q6 Is there an ITP specialist nurse in the clinic? (Yes / No / Don't know)

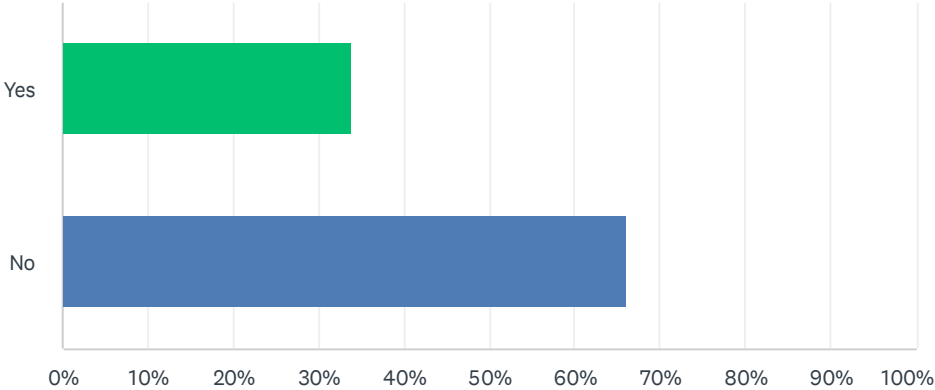
Answered: 133 Skipped: 1



ANSWER CHOICES	RESPONSES
Yes	47.37% 63
No	18.05% 24
Don't know	34.59% 46
Total Respondents: 133	

Q7 Did your GP have knowledge of ITP when you first sought advice for your symptoms?

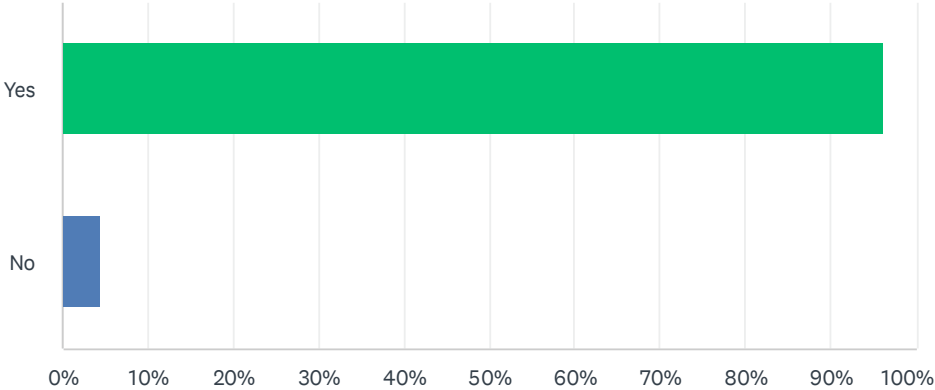
Answered: 130 Skipped: 4



ANSWER CHOICES	RESPONSES	
Yes	33.85%	44
No	66.15%	86
Total Respondents: 130		

Q8 Are the staff at your ITP Centre friendly, polite and attentive? (Yes / No)

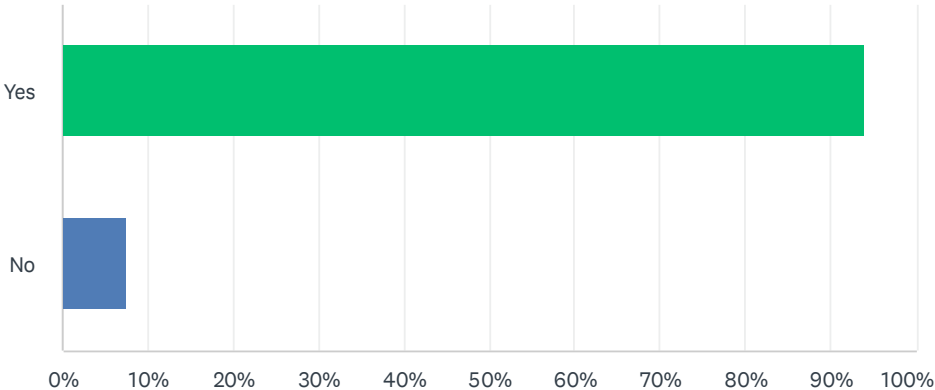
Answered: 132 Skipped: 2



ANSWER CHOICES	RESPONSES
Yes	96.21% 127
No	4.55% 6
Total Respondents: 132	

Q9 Are you given time to ask questions or express concerns? (Yes / No)

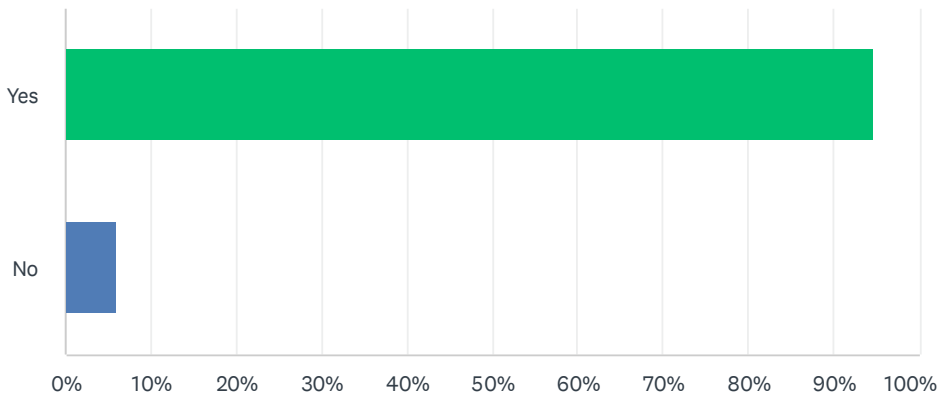
Answered: 133 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	93.98%	125
No	7.52%	10
Total Respondents: 133		

Q10 Do the team in charge of your care attempt to answer your questions (bearing in mind much is unknown in ITP) (Yes / No)

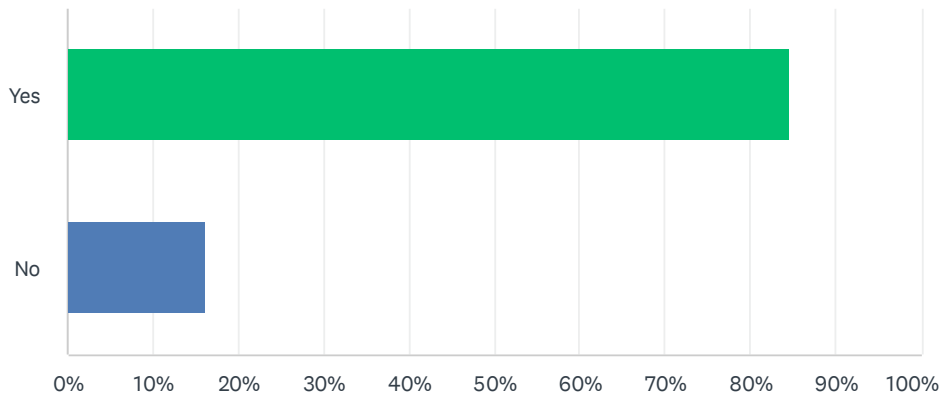
Answered: 133 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	94.74%	126
No	6.02%	8
Total Respondents: 133		

Q11 Are you happy with your doctor's efforts to manage your ITP? (Yes / No) If No please give some detail in the comment field.

Answered: 130 Skipped: 4



ANSWER CHOICES	RESPONSES	
Yes	84.62%	110
No	16.15%	21
Total Respondents: 130		

Q12 Have you ever been prescribed a treatment for your ITP that you felt wasn't as a result of a co-decision between yourself and your doctor?
Please answer Yes or No plus any comments if you would like to add more detail.

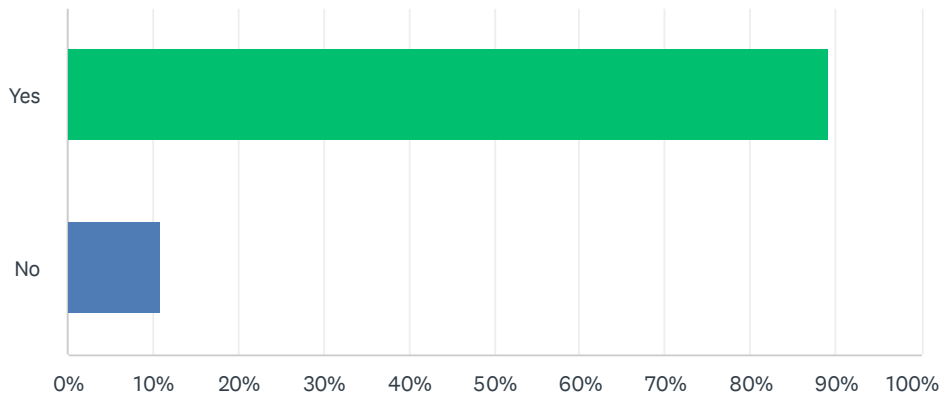
Answered: 132 Skipped: 2

Q13 Have you ever been refused any ITP treatment you did want? (Yes / No), If yes please add further detail.

Answered: 131 Skipped: 3

Q14 Have you been given clear instructions about any medications and know that you need to take them as prescribed. (Yes / No)

Answered: 130 Skipped: 4



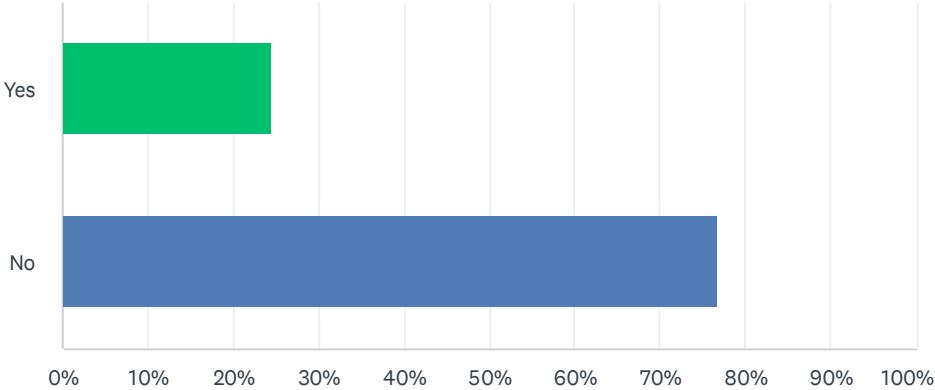
ANSWER CHOICES	RESPONSES	
Yes	89.23%	116
No	10.77%	14
Total Respondents: 130		

**Q15 Were you told about any possible side effects from your medication?
(Yes / No) If Yes, please highlight what side effects?**

Answered: 127 Skipped: 7

Q16 Have you been offered the opportunity to take part in any clinical trials or studies? (Yes / No)

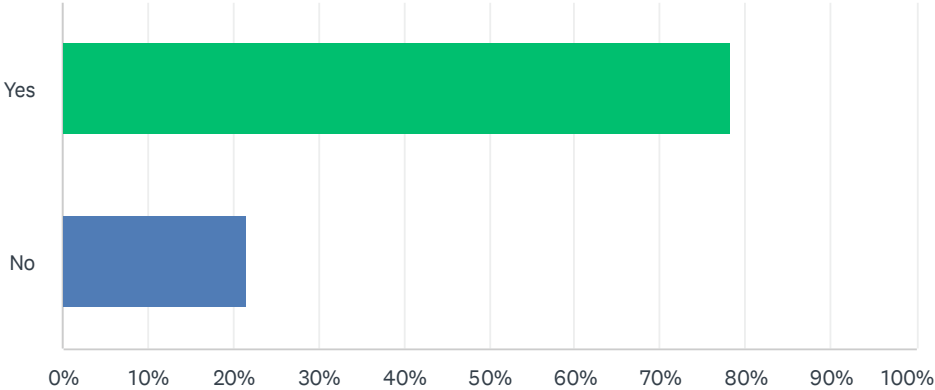
Answered: 134 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	24.63%	33
No	76.87%	103
Total Respondents: 134		

Q17 Have you been given a number to ring in case of emergencies or urgent enquiries? (Yes / No)

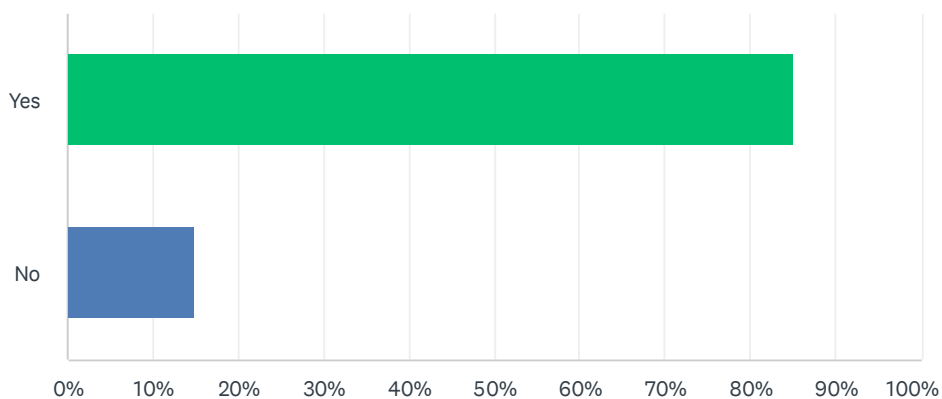
Answered: 134 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	78.36%	105
No	21.64%	29
Total Respondents: 134		

Q18 Has the overall quality of care met your expectations? (Yes / No)

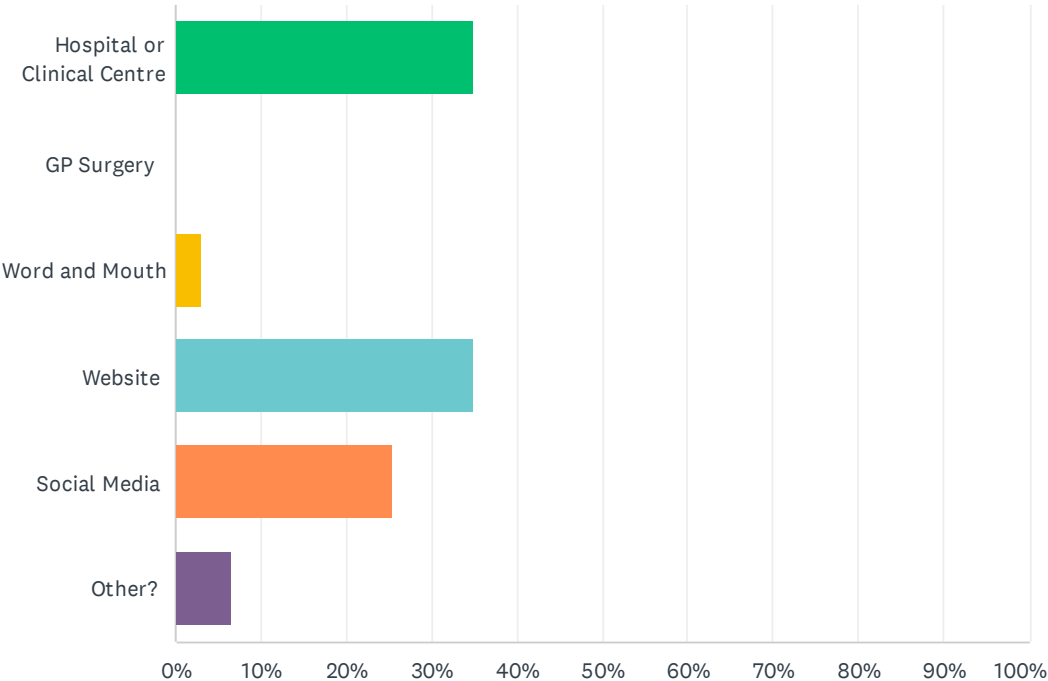
Answered: 134 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	85.07%	114
No	14.93%	20
Total Respondents: 134		

Q19 Where did you hear about the ITP Support Association?

Answered: 134 Skipped: 0



ANSWER CHOICES	RESPONSES	
Hospital or Clinical Centre	35.07%	47
GP Surgery	0.00%	0
Word and Mouth	2.99%	4
Website	35.07%	47
Social Media	25.37%	34
Other?	6.72%	9
Total Respondents: 134		

Q20 If you asked to be referred to an ITP Centre from your local hospital please list up to 3 reasons why you prefer the ITP Centre:-

Answered: 34 Skipped: 100

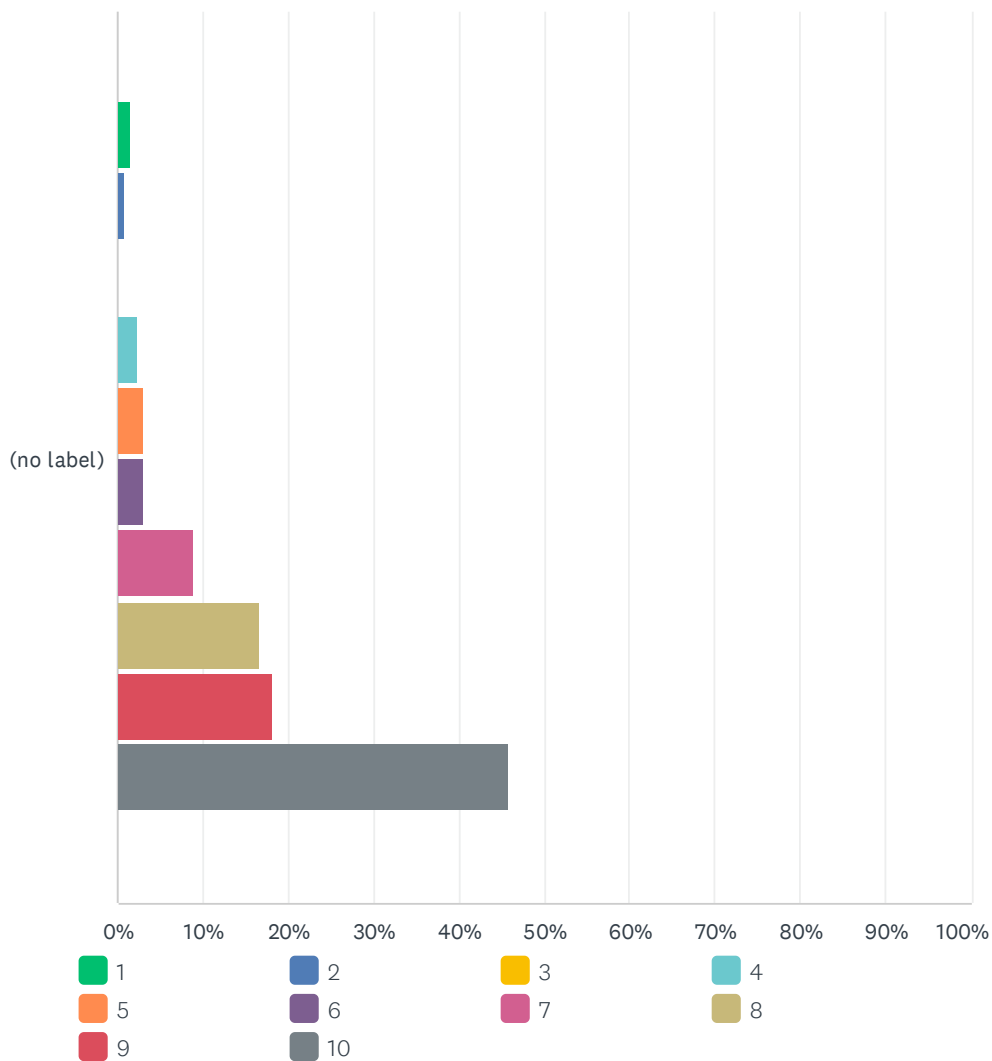
ANSWER CHOICES	RESPONSES	
1	100.00%	34
2	67.65%	23
3	58.82%	20

Q21 Do you have any suggestions for improvements that could be made at your Hospital or ITP Centre?

Answered: 79 Skipped: 55

Q22 On a scale of 1 to 10 (1 = very poor, 10 = first class) what number would you use to rate the standard of care at your Hospital or ITP Clinical Centre.

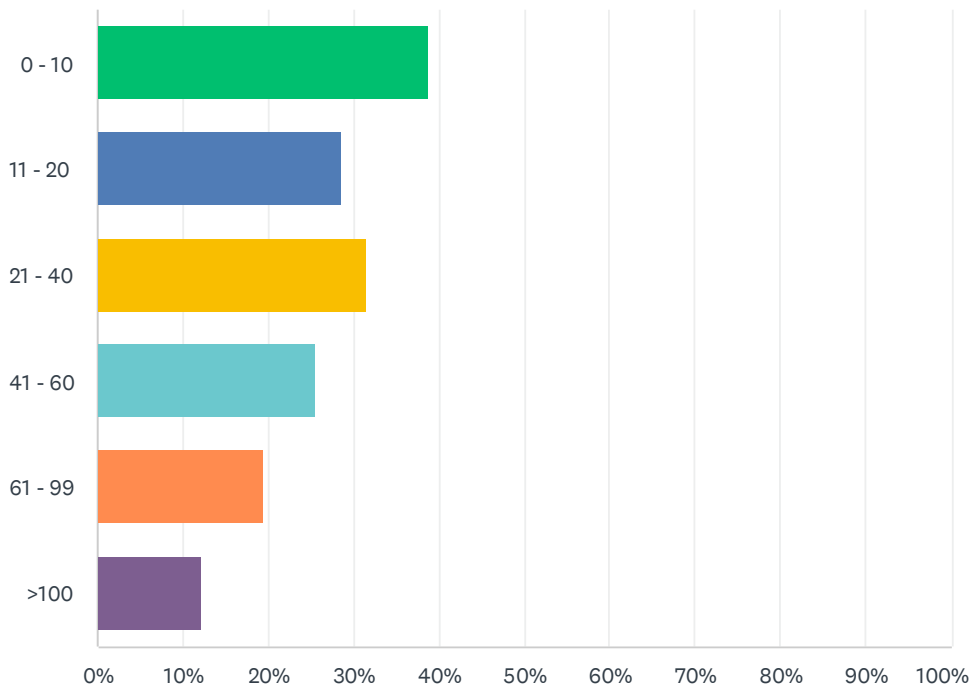
Answered: 133 Skipped: 1



	1	2	3	4	5	6	7	8	9	10	TOTAL	WEIGHTED AVERAGE
(no label)	1.50%	0.75%	0.00%	2.26%	3.01%	3.01%	9.02%	16.54%	18.05%	45.86%	133	8.62
	2	1	0	3	4	4	12	22	24	61		

Q23 If you experience fatigue as one of your symptoms, did you know what your Platelet Level was at the time? If yes please tick the appropriate box

Answered: 98 Skipped: 36



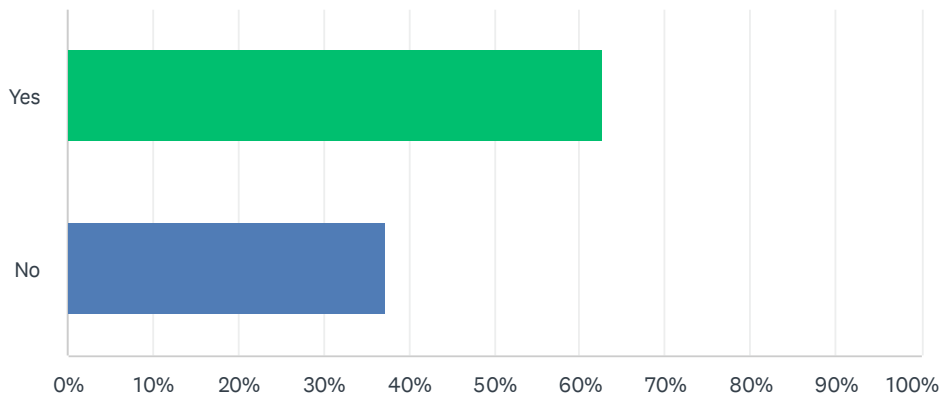
ANSWER CHOICES	RESPONSES	
0 - 10	38.78%	38
11 - 20	28.57%	28
21 - 40	31.63%	31
41 - 60	25.51%	25
61 - 99	19.39%	19
>100	12.24%	12
Total Respondents: 98		

Q24 Patients always highlight the effect of ITP on their Quality of Life (QOL), what are the major effects on your QOL as a result of ITP

Answered: 132 Skipped: 2

Q25 Another issue highlighted by many who attend ITP Patient Support Groups is the effects of ITP on a patients mental health. Has ITP had an effect on your mental wellbeing?

Answered: 131 Skipped: 3



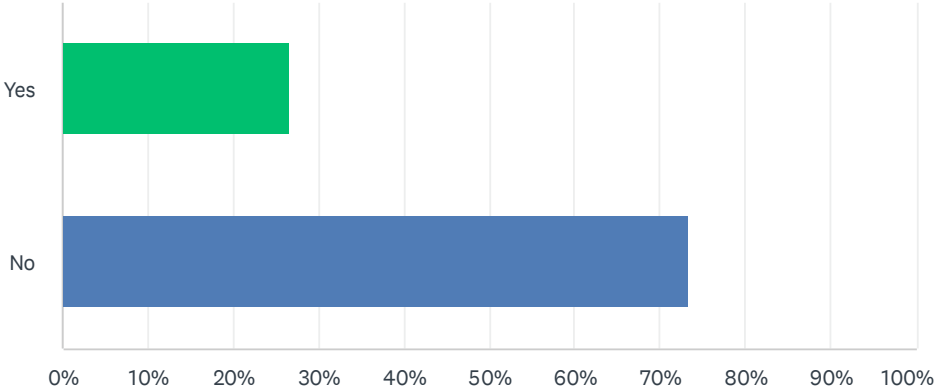
ANSWER CHOICES	RESPONSES
Yes	62.60% 82
No	37.40% 49
Total Respondents: 131	

Q26 If you answered yes to Q25 please give some details of the effects on your mental health?

Answered: 83 Skipped: 51

Q27 If you answered yes to Q26, have you received any support from a Health Care Professional for your mental health?

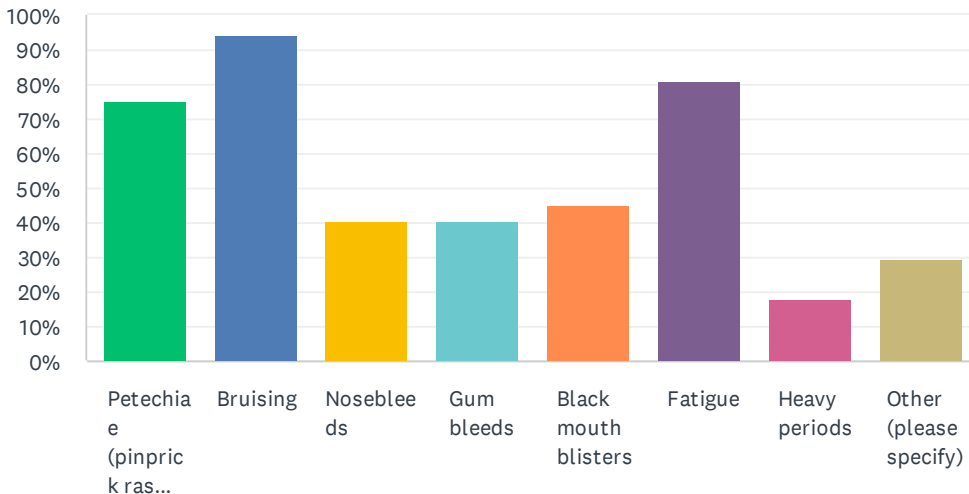
Answered: 90 Skipped: 44



ANSWER CHOICES	RESPONSES	
Yes	26.67%	24
No	73.33%	66
Total Respondents: 90		

Q28 Please indicate which other common symptoms you associate with your ITP?

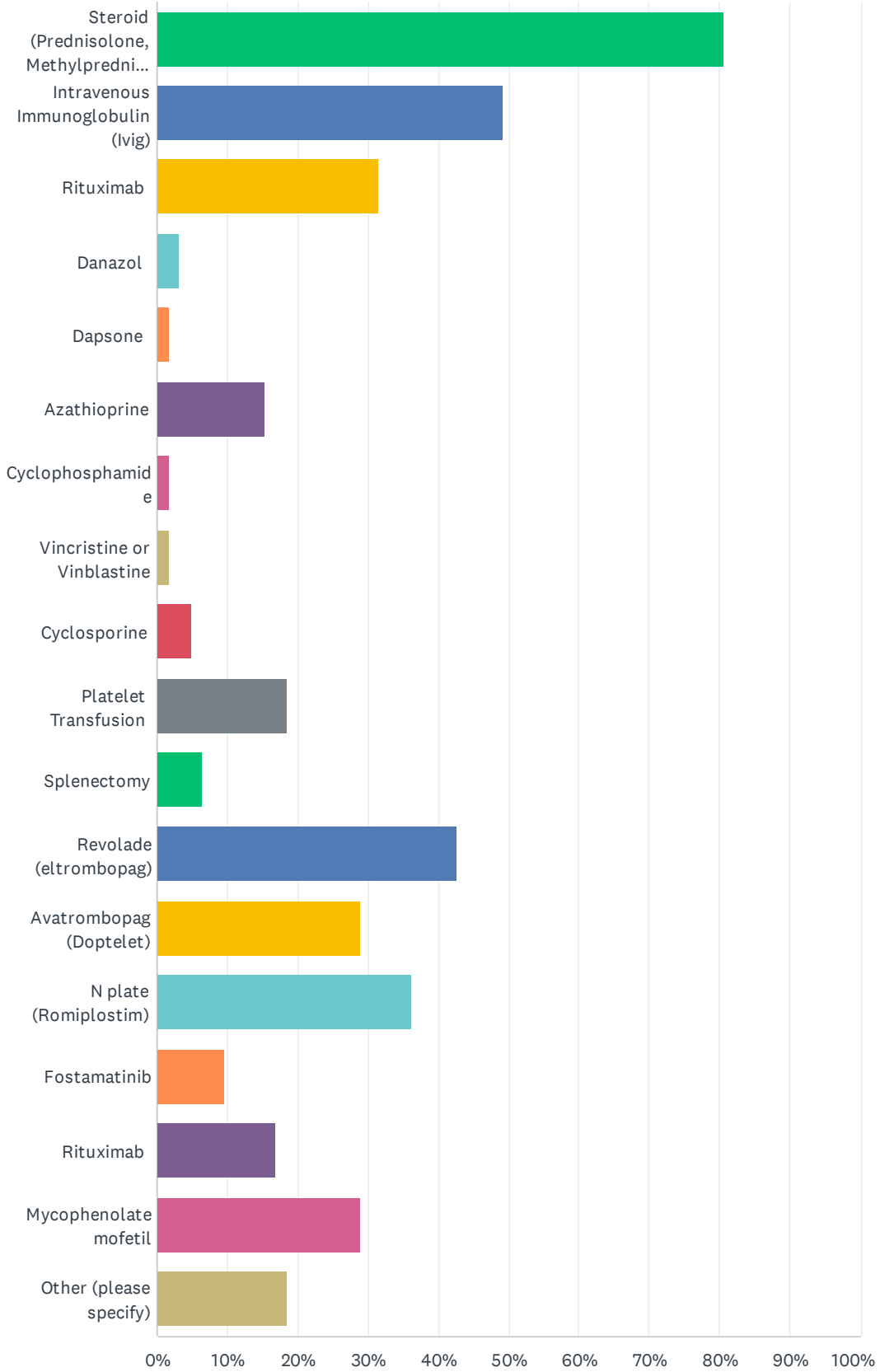
Answered: 133 Skipped: 1



ANSWER CHOICES	RESPONSES	
Petechiae (pinprick rash of blood spots)	75.19%	100
Bruising	93.98%	125
Nosebleeds	40.60%	54
Gum bleeds	40.60%	54
Black mouth blisters	45.11%	60
Fatigue	81.20%	108
Heavy periods	18.05%	24
Other (please specify)	29.32%	39
Total Respondents: 133		

Q29 Please tick which medication or treatment you have received for your ITP?

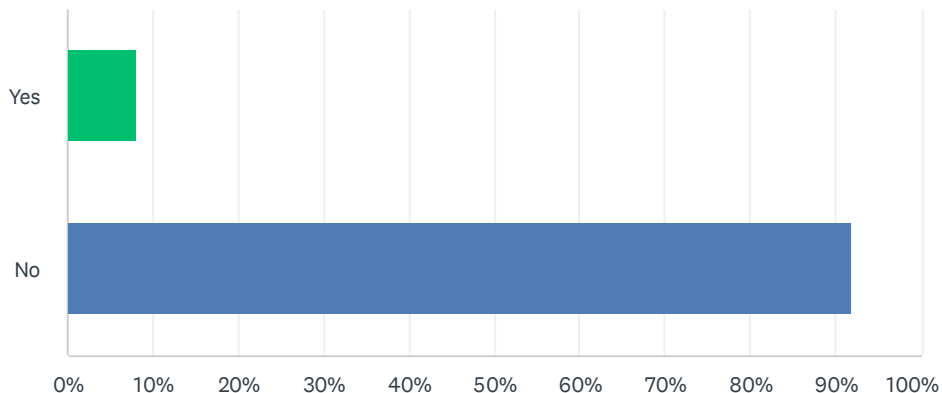
Answered: 124 Skipped: 10



ANSWER CHOICES	RESPONSES	
Steroid (Prednisolone, Methylprednisolone, Dexamethasone)	80.65%	100
Intravenous Immunoglobulin (Ivlg)	49.19%	61
Rituximab	31.45%	39
Danazol	3.23%	4
Dapsone	1.61%	2
Azathioprine	15.32%	19
Cyclophosphamide	1.61%	2
Vincristine or Vinblastine	1.61%	2
Cyclosporine	4.84%	6
Platelet Transfusion	18.55%	23
Splenectomy	6.45%	8
Revolade (eltrombopag)	42.74%	53
Avatrombopag (Doptelet)	29.03%	36
N plate (Romiplostim)	36.29%	45
Fostamatinib	9.68%	12
Rituximab	16.94%	21
Mycophenolate mofetil	29.03%	36
Other (please specify)	18.55%	23
Total Respondents: 124		

Q30 Some patients have described issues with obtaining standard second line NICE approved treatments TPO/RA (Such as Romiplostim, Eltrombopag etc) in their area, have you experienced this problem? Yes or No

Answered: 125 Skipped: 9



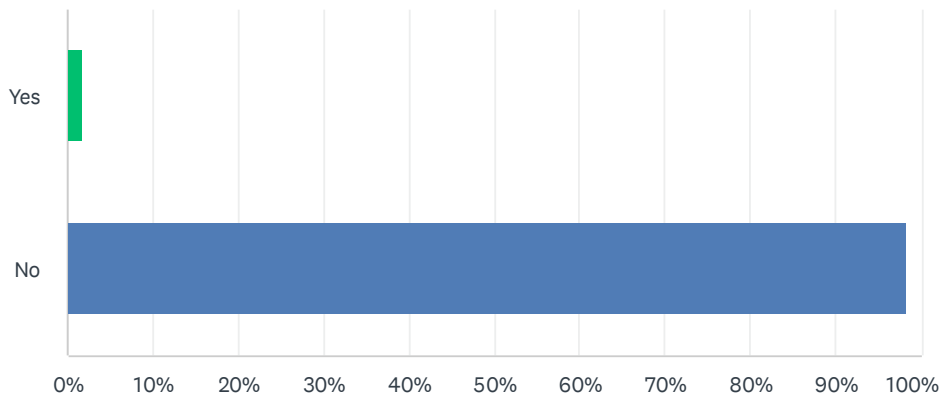
ANSWER CHOICES	RESPONSES
Yes	8.00% 10
No	92.00% 115
TOTAL	125

Q31 If you answered Yes to Question 30 could you give us the name of your Hospital Trust.

Answered: 14 Skipped: 120

Q32 Some patients have reported that they have been offered a choice of two TPO/RA treatments, however if their first choice does not work they have to apply via a IFR (Individual Funding Request) before the second TPO/RA can be prescribed, has this happened to you? Yes or No

Answered: 118 Skipped: 16



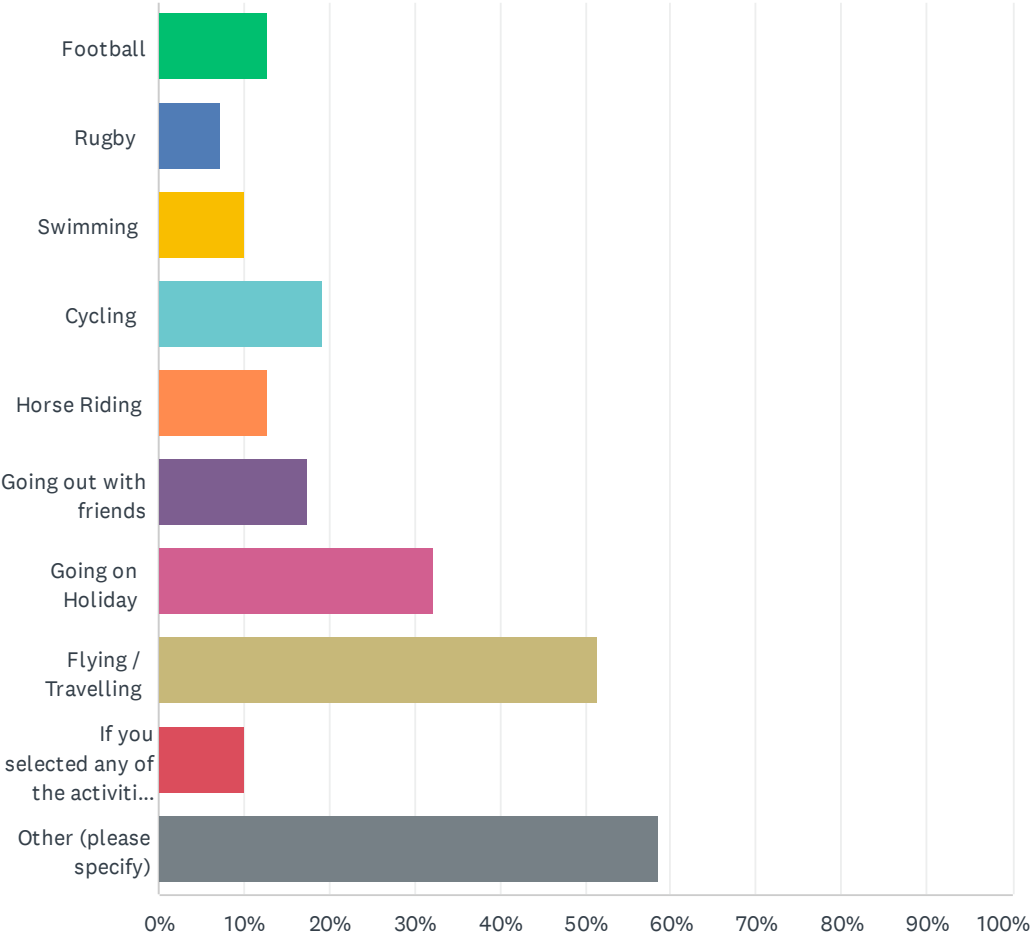
ANSWER CHOICES	RESPONSES
Yes	1.69% 2
No	98.31% 116
TOTAL	118

Q33 Following on from the previous question, have you ever had an IFR (Individual Funding Request) for ITP Treatment rejected? If yes, what was the reason given?

Answered: 42 Skipped: 92

Q34 As a result of your ITP please tell us what activities you feel you no longer able to do?

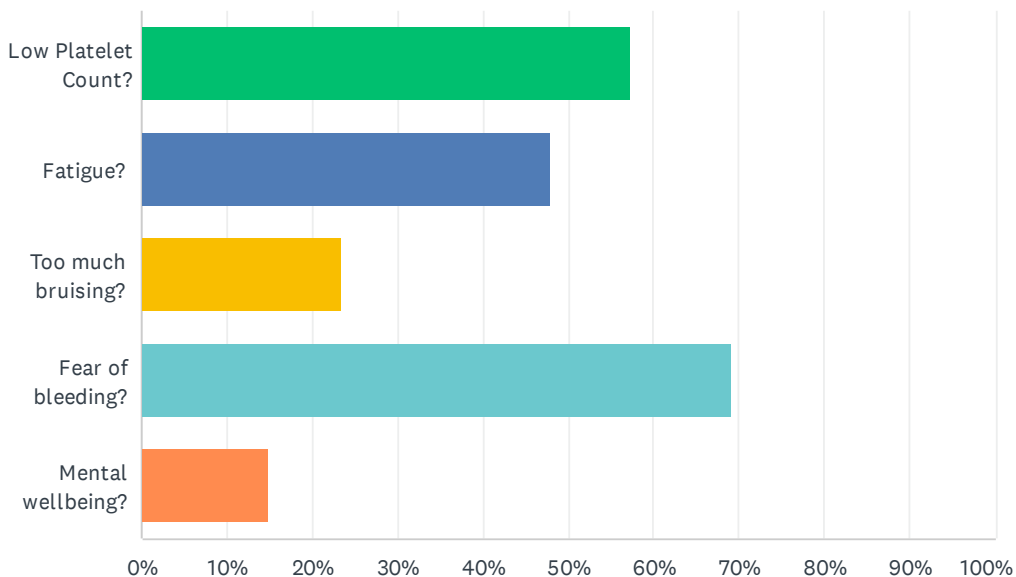
Answered: 109 Skipped: 25



ANSWER CHOICES	RESPONSES	
Football	12.84%	14
Rugby	7.34%	8
Swimming	10.09%	11
Cycling	19.27%	21
Horse Riding	12.84%	14
Going out with friends	17.43%	19
Going on Holiday	32.11%	35
Flying / Travelling	51.38%	56
If you selected any of the activities in this question was this under advisement from a Health Care Professional.	10.09%	11
Other (please specify)	58.72%	64
Total Respondents: 109		

Q35 If you have been unable to do an activity as answered in Question 34, what was the main reason for your answer?

Answered: 94 Skipped: 40



ANSWER CHOICES	RESPONSES	
Low Platelet Count?	57.45%	54
Fatigue?	47.87%	45
Too much bruising?	23.40%	22
Fear of bleeding?	69.15%	65
Mental wellbeing?	14.89%	14
Total Respondents: 94		

Q36 If you have any points you would like included in future surveys please provide the details here.

Answered: 24 Skipped: 110

Q37 Please provide your Postal Code

Answered: 131 Skipped: 3