

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

Answered: 0 Skipped: 194

 No matching responses.

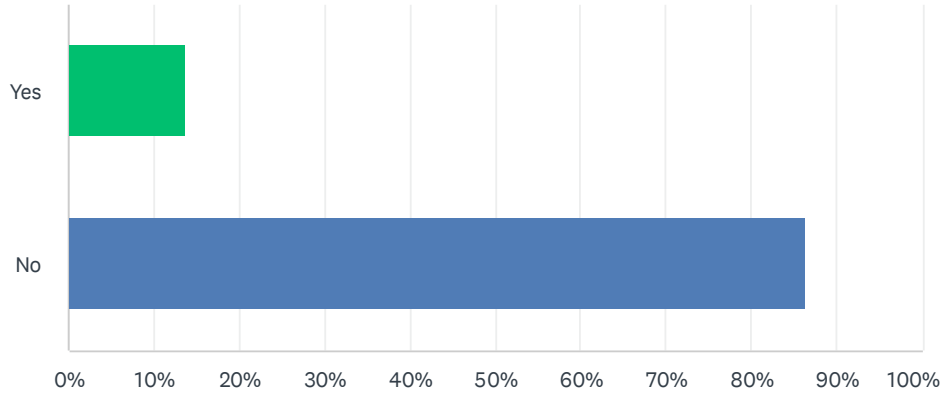
ANSWER CHOICES	RESPONSES
Patient	0.00% 0
Carer	0.00% 0
Parent	0.00% 0
Total Respondents: 0	

## Q2 Your Hospital or ITP Specialist Centre Name:

Answered: 189 Skipped: 5

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

Answered: 190 Skipped: 4



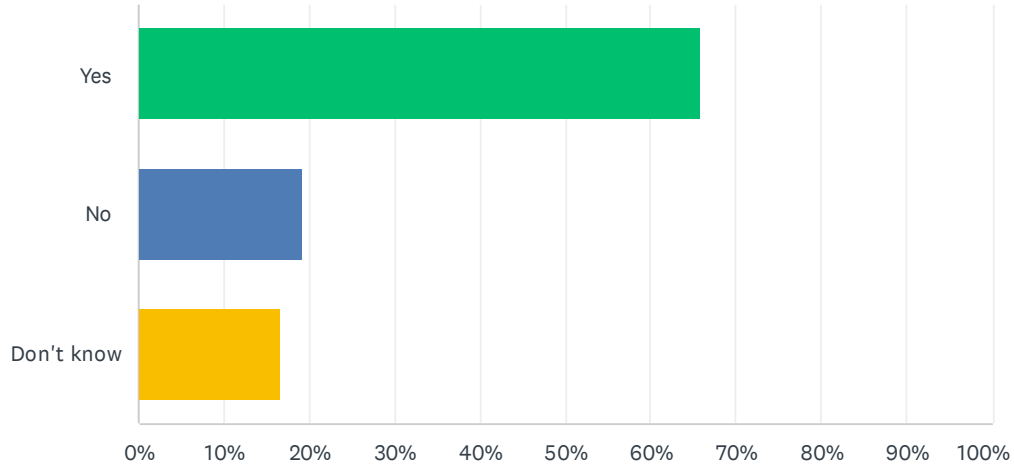
ANSWER CHOICES	RESPONSES	
Yes	13.68%	26
No	86.32%	164
Total Respondents: 190		

## Q4 What is the name of the doctor in charge of your care?

Answered: 175 Skipped: 19

## Q5 Does your doctor have a treatment plan for you? (Yes / No / Don't know)

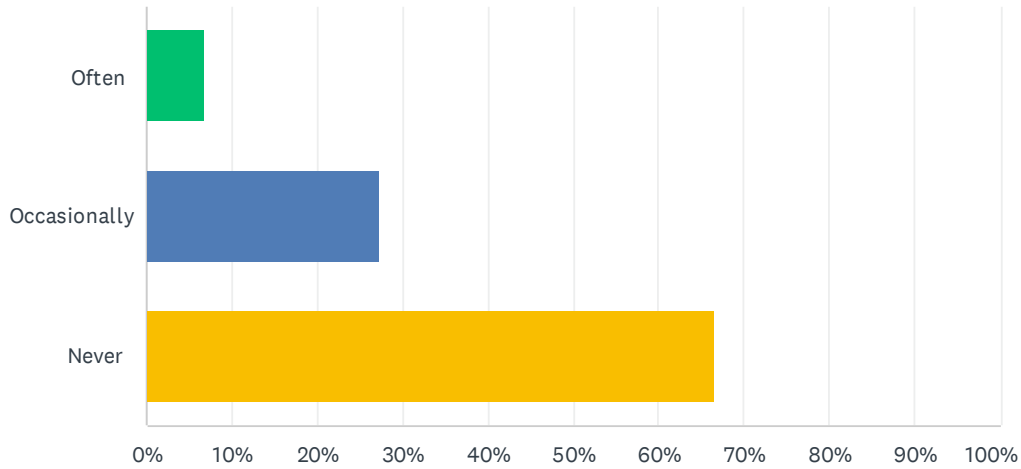
Answered: 193 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	65.80%	127
No	19.17%	37
Don't know	16.58%	32
Total Respondents: 193		

## Q6 Have you ever had conflicting advice from different doctors in the team? (Often / Occasionally / Never)

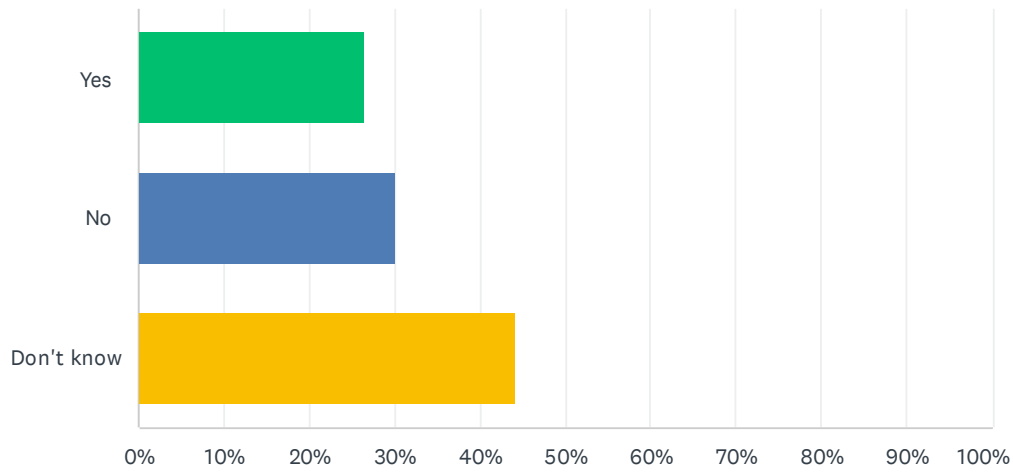
Answered: 191 Skipped: 3



ANSWER CHOICES	RESPONSES	
Often	6.81%	13
Occasionally	27.23%	52
Never	66.49%	127
Total Respondents: 191		

### Q7 Is there an ITP specialist nurse in the clinic? (Yes / No / Don't know)

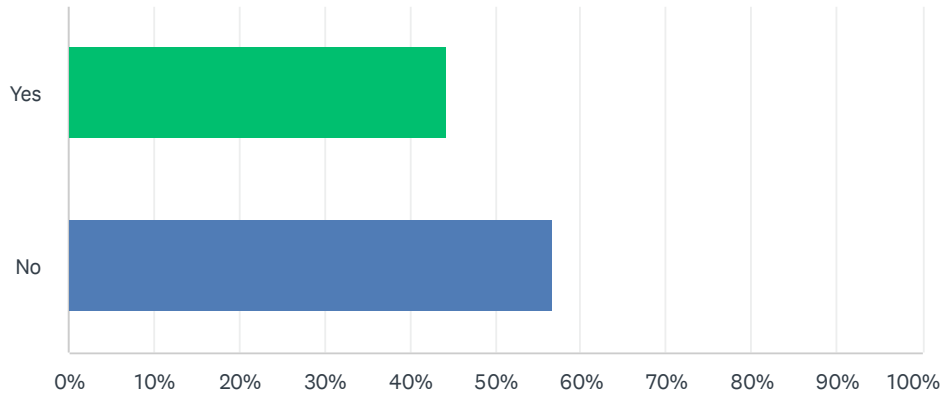
Answered: 193 Skipped: 1



ANSWER CHOICES	RESPONSES
Yes	26.42% 51
No	30.05% 58
Don't know	44.04% 85
Total Respondents: 193	

## Q8 Did your GP have knowledge of ITP when you first sought advice for your symptoms?

Answered: 185 Skipped: 9

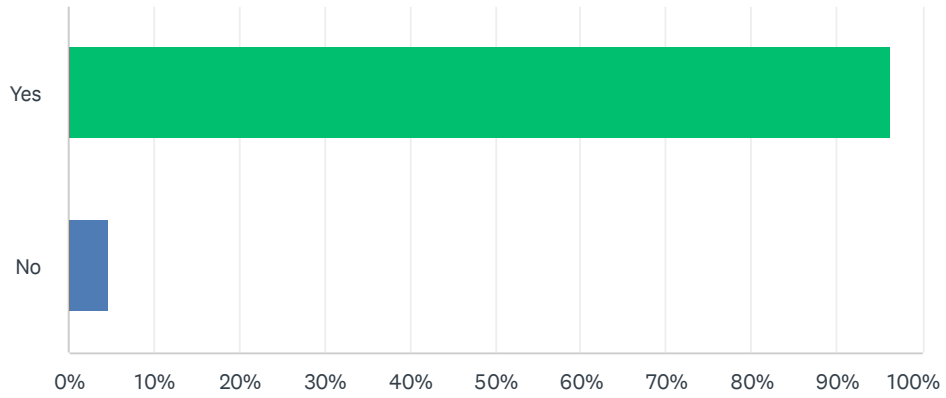


ANSWER CHOICES	RESPONSES	
Yes	44.32%	82
No	56.76%	105
Total Respondents: 185		



## Q9 Are the staff at your GP Surgery, Hospital or ITP Centre friendly, polite and attentive? (Yes / No)

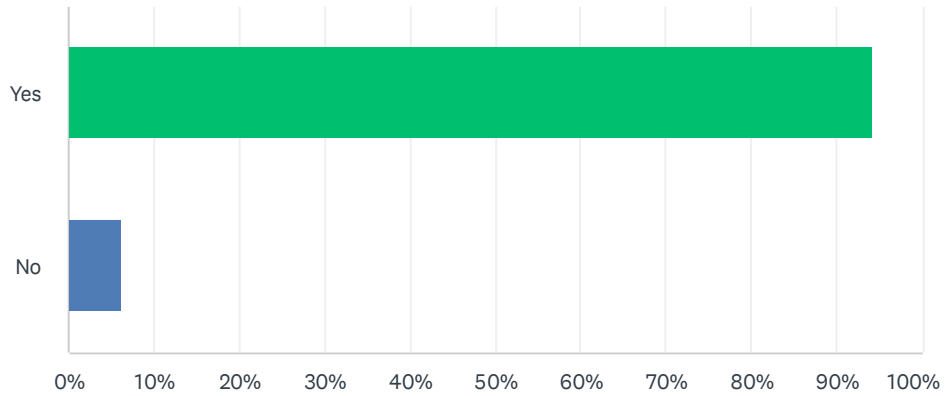
Answered: 191 Skipped: 3



ANSWER CHOICES	RESPONSES	
Yes	96.34%	184
No	4.71%	9
Total Respondents: 191		

## Q10 Are you given time to ask questions or express concerns? (Yes / No)

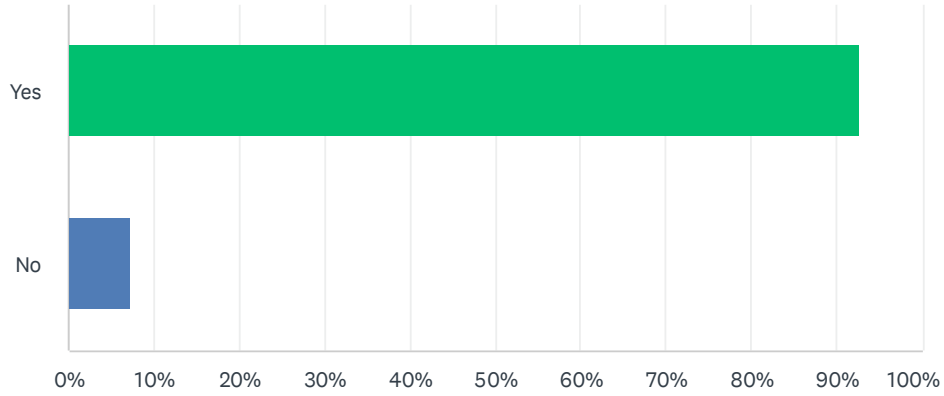
Answered: 193 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	94.30%	182
No	6.22%	12
Total Respondents: 193		

### Q11 Do the team in charge of your care attempt to answer your questions (bearing in mind much is unknown in ITP) (Yes / No)

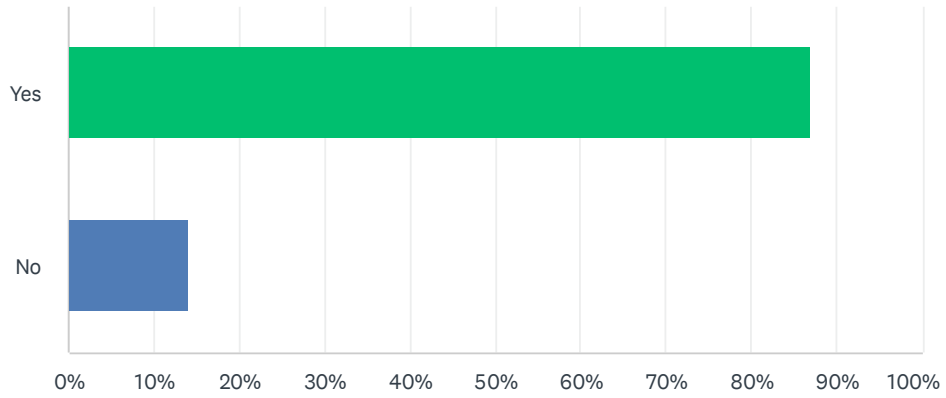
Answered: 193 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	92.75%	179
No	7.25%	14
Total Respondents: 193		

## Q12 Are you happy with your doctor's efforts to manage your ITP? (Yes / No)

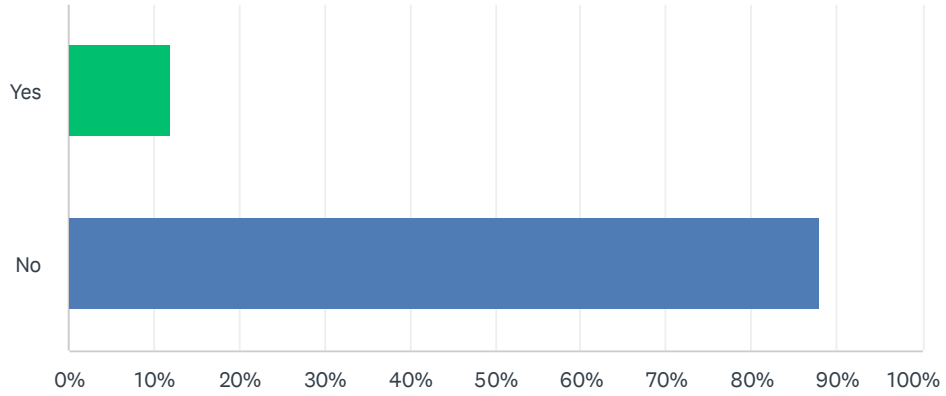
Answered: 193 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	87.05%	168
No	13.99%	27
Total Respondents: 193		

### Q13 Have you ever been pushed into having an ITP treatment you didn't want? (Yes / No)

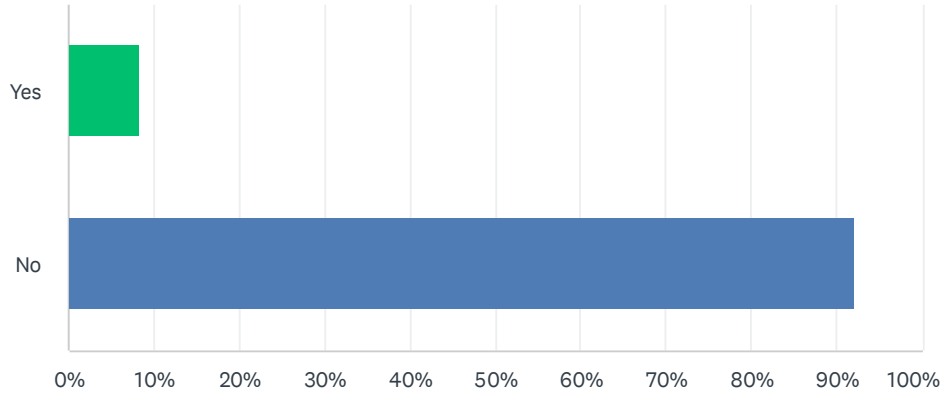
Answered: 192 Skipped: 2



ANSWER CHOICES	RESPONSES	
Yes	11.98%	23
No	88.02%	169
Total Respondents: 192		

### Q14 Have you ever been refused any ITP treatment you did want? (Yes / No)

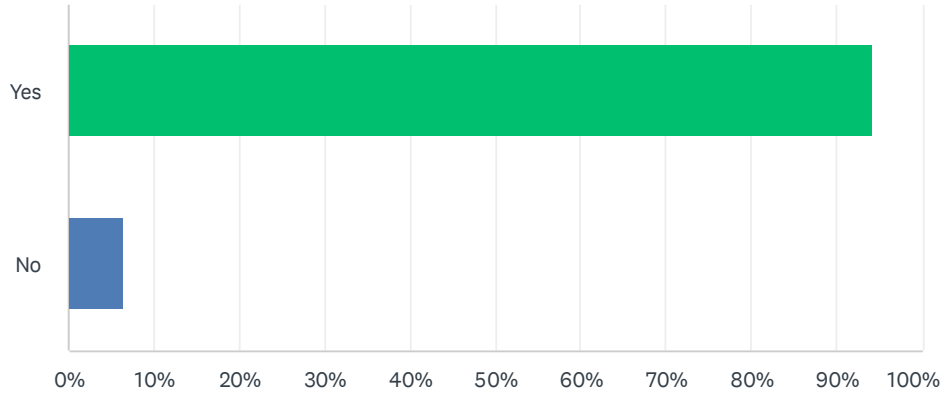
Answered: 192 Skipped: 2



ANSWER CHOICES	RESPONSES	
Yes	8.33%	16
No	92.19%	177
Total Respondents: 192		

### Q15 Have you been given clear instructions about any medications and know that you need to take them as prescribed. (Yes / No)

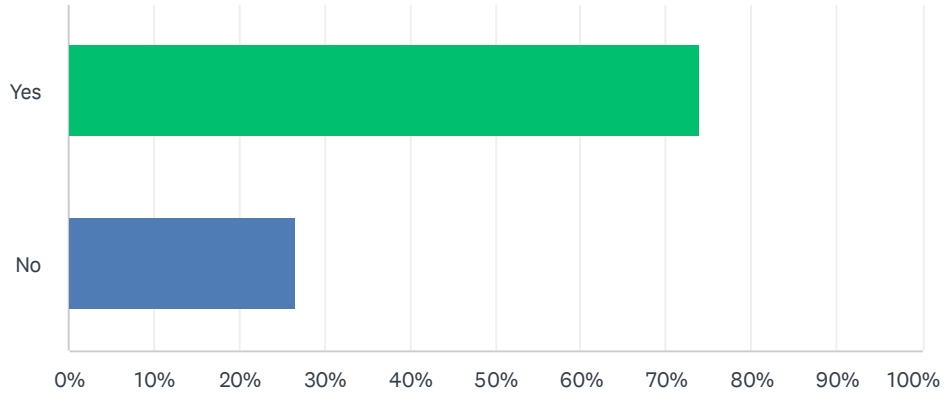
Answered: 190 Skipped: 4



ANSWER CHOICES	RESPONSES	
Yes	94.21%	179
No	6.32%	12
Total Respondents: 190		

## Q16 Were you told about any possible side effects from your medication? (Yes / No)

Answered: 188 Skipped: 6

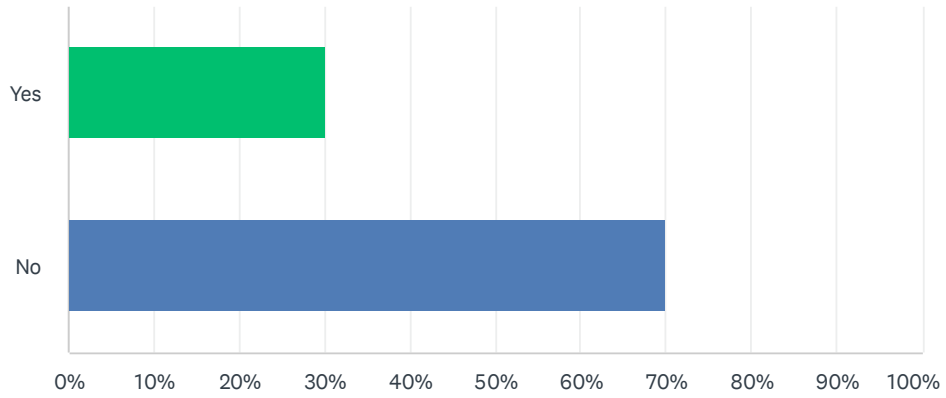


ANSWER CHOICES	RESPONSES	
Yes	73.94%	139
No	26.60%	50
Total Respondents: 188		



### Q17 Have you been offered the opportunity to take part in any clinical trials or studies? (Yes / No)

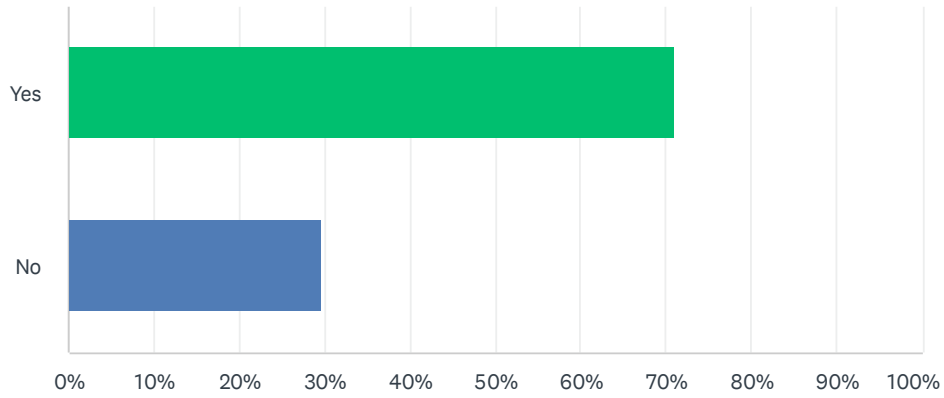
Answered: 193 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	30.05%	58
No	69.95%	135
Total Respondents: 193		

## Q18 Have you been given a number to ring in case of emergencies or urgent enquiries? (Yes / No)

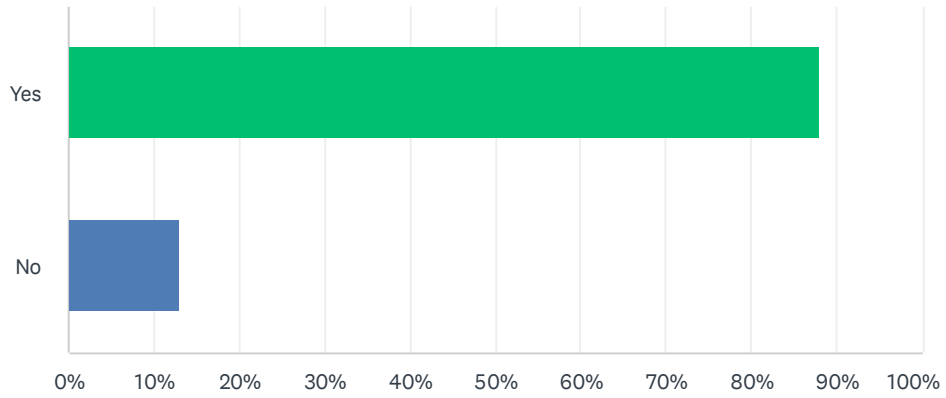
Answered: 193 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	70.98%	137
No	29.53%	57
Total Respondents: 193		

### Q19 Has the overall quality of care met your expectations? (Yes / No)

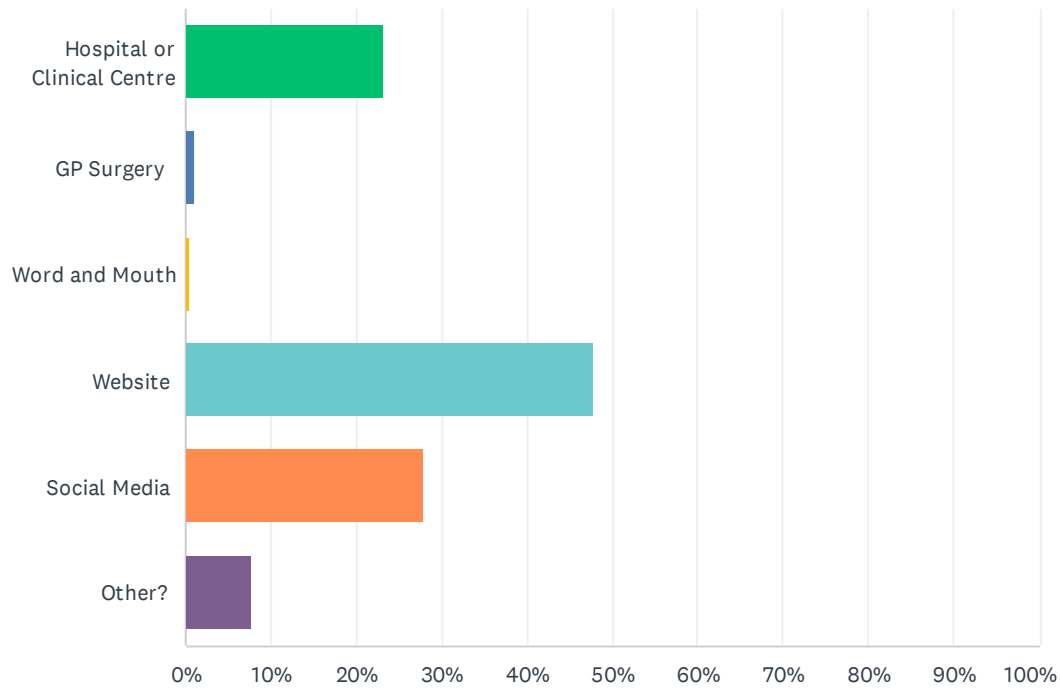
Answered: 193 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	88.08%	170
No	12.95%	25
Total Respondents: 193		

## Q20 Where did you hear about the ITP Support Association?

Answered: 193 Skipped: 1



ANSWER CHOICES	RESPONSES
Hospital or Clinical Centre	23.32% 45
GP Surgery	1.04% 2
Word and Mouth	0.52% 1
Website	47.67% 92
Social Media	27.98% 54
Other?	7.77% 15
Total Respondents: 193	

## Q21 If you were referred to an ITP Centre from your local hospital please list up to 3 reasons why you prefer the ITP Centre:-

Answered: 39 Skipped: 155

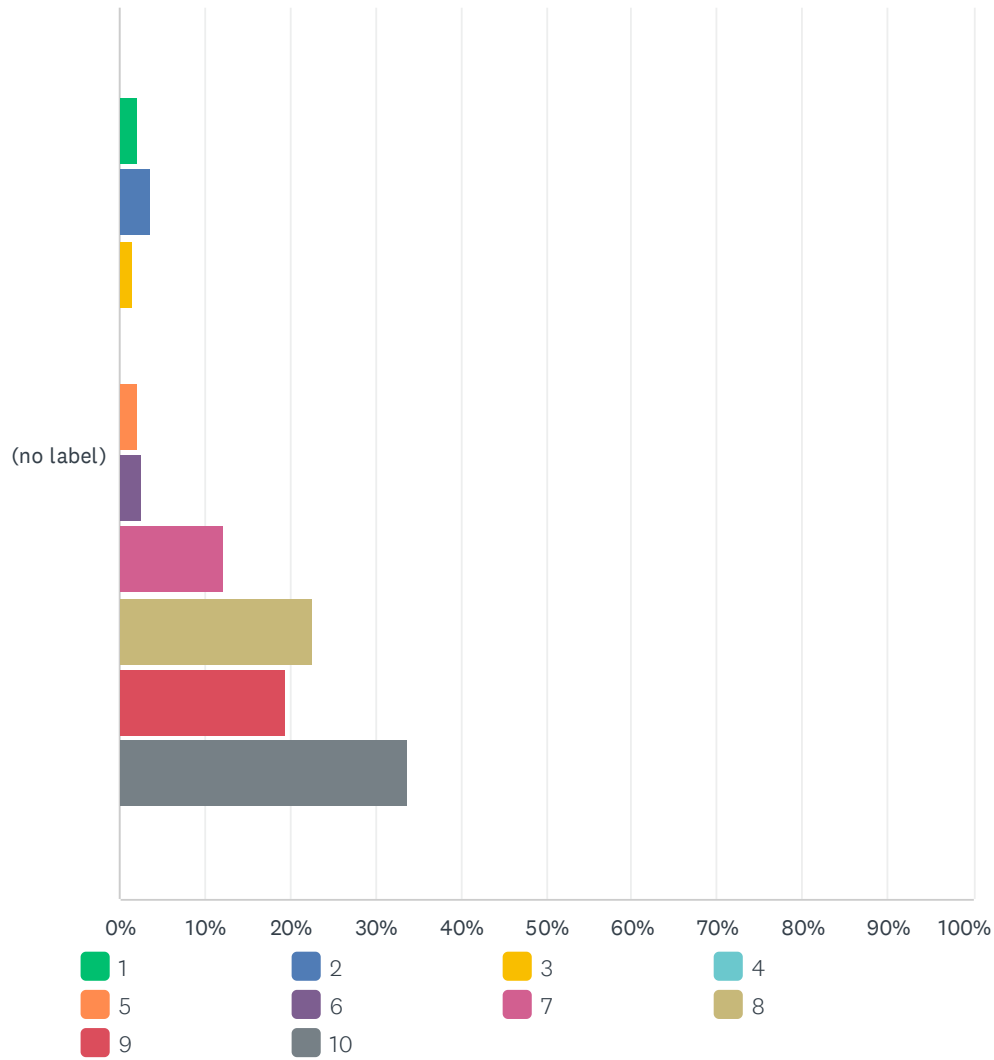
ANSWER CHOICES	RESPONSES	
1	100.00%	39
2	69.23%	27
3	53.85%	21

**Q22 Do you have any suggestions for improvements that could be made at your Hospital or ITP Centre?**

Answered: 93 Skipped: 101

### Q23 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.

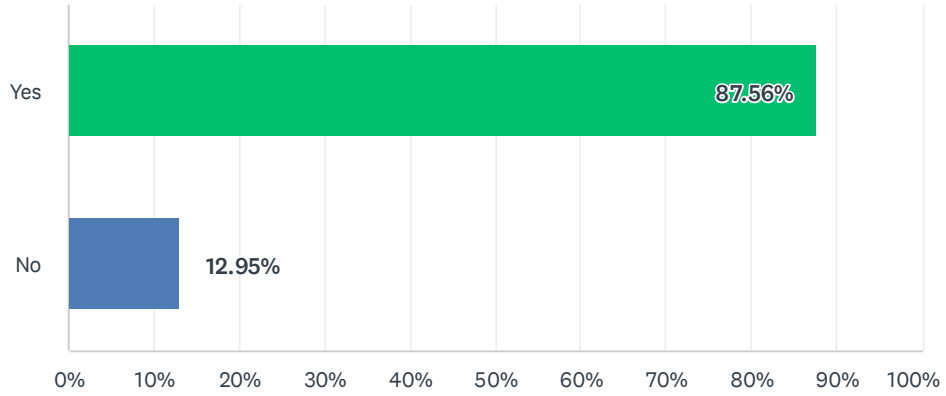
Answered: 190 Skipped: 4



	1	2	3	4	5	6	7	8	9	10	TOTAL	WEIGHTED AVERAGE
(no label)	2.11% 4	3.68% 7	1.58% 3	0.00% 0	2.11% 4	2.63% 5	12.11% 23	22.63% 43	19.47% 37	33.68% 64	190	8.18

## Q24 Fatigue is highlighted by Patients as one of the top issues with the condition, do you experience fatigue?

Answered: 193 Skipped: 1

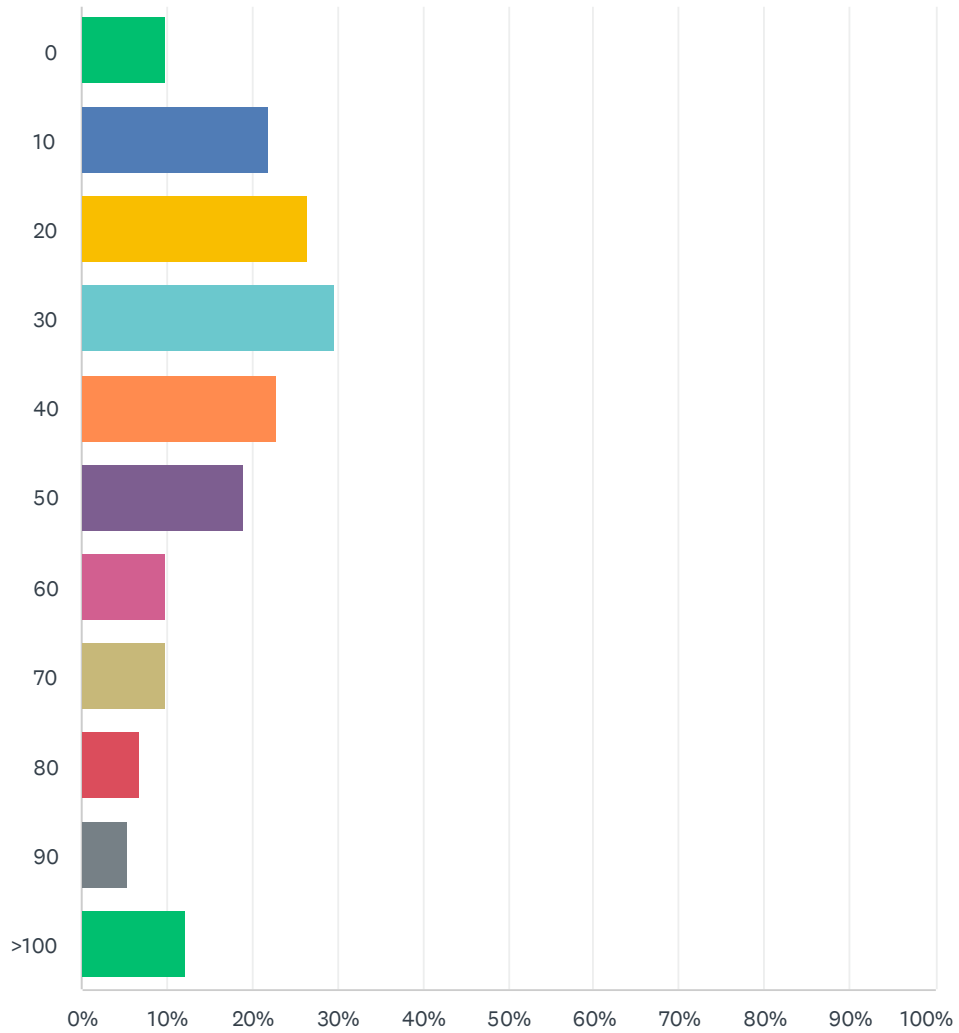


ANSWER CHOICES	RESPONSES	
Yes	87.56%	169
No	12.95%	25
Total Respondents: 193		



### Q25 If you answered yes to question 24, when you experience fatigue did you know your Platelet Level? If yes please tick the appropriate box

Answered: 132 Skipped: 62



ITP Support Association Patient Perception Survey 2020

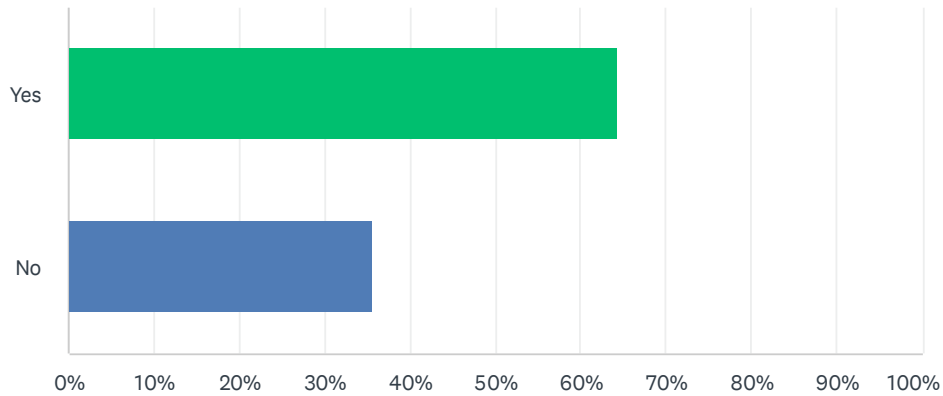
ANSWER CHOICES	RESPONSES	
0	9.85%	13
10	21.97%	29
20	26.52%	35
30	29.55%	39
40	22.73%	30
50	18.94%	25
60	9.85%	13
70	9.85%	13
80	6.82%	9
90	5.30%	7
>100	12.12%	16
Total Respondents: 132		

**Q26 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: 171 Skipped: 23

### Q27 Another issue highlighted by many who attend ITP Local Groups is the effects of ITP on a patients mental health. Has ITP had an effect on your mental wellbeing?

Answered: 188 Skipped: 6



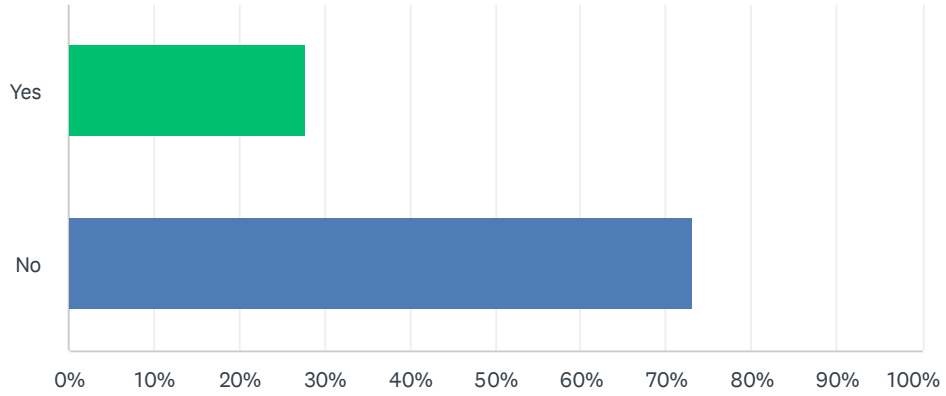
ANSWER CHOICES	RESPONSES	
Yes	64.36%	121
No	35.64%	67
Total Respondents: 188		

**Q28 If you answered yes to Q27 please give some details of the effects on your mental health?**

Answered: 123 Skipped: 71

## Q29 If you answered yes to Q27, have you received any support from a Health Care Professional for your mental health?

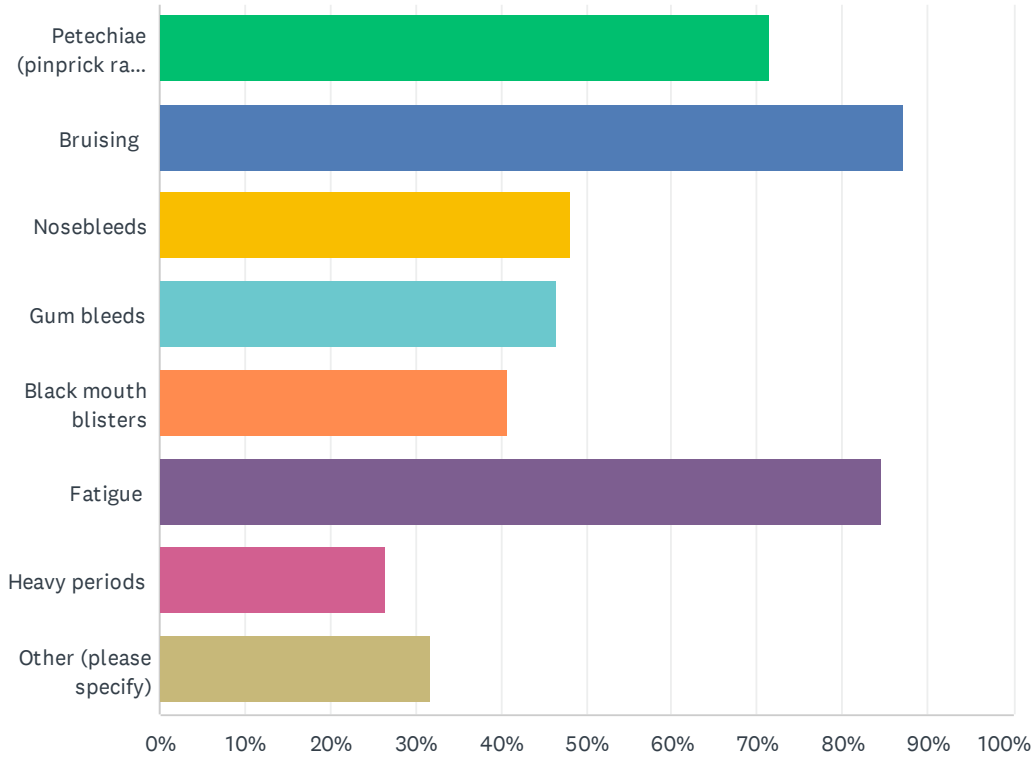
Answered: 123 Skipped: 71



ANSWER CHOICES	RESPONSES	
Yes	27.64%	34
No	73.17%	90
Total Respondents: 123		

## Q30 Please indicate which other common symptoms you associate with your ITP?

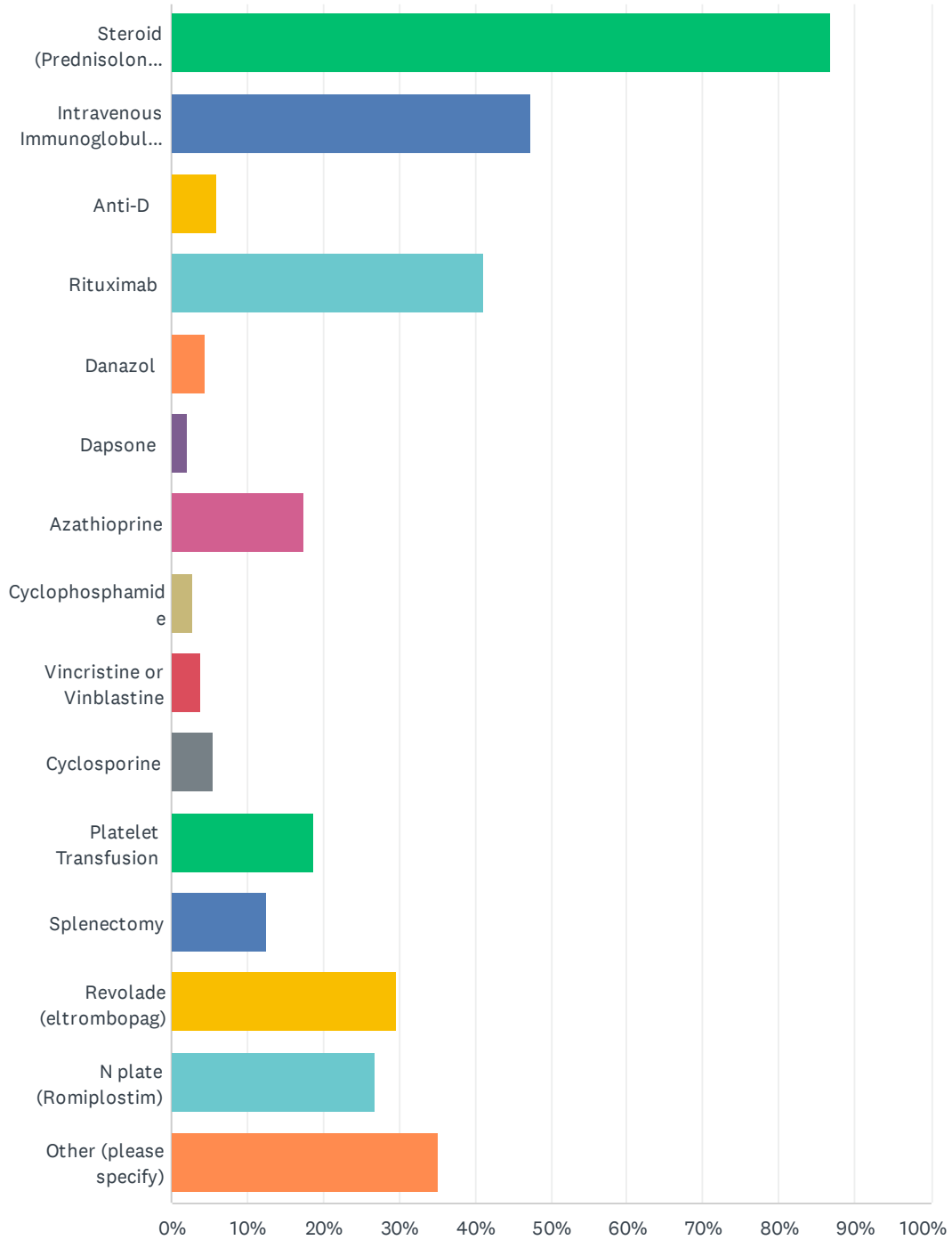
Answered: 189 Skipped: 5



ANSWER CHOICES	RESPONSES	
Petechiae (pinprick rash of blood spots)	71.43%	135
Bruising	87.30%	165
Nosebleeds	48.15%	91
Gum bleeds	46.56%	88
Black mouth blisters	40.74%	77
Fatigue	84.66%	160
Heavy periods	26.46%	50
Other (please specify)	31.75%	60
Total Respondents: 189		

## Q31 Please tick which medication or treatment you have received for your ITP?

Answered: 182 Skipped: 12



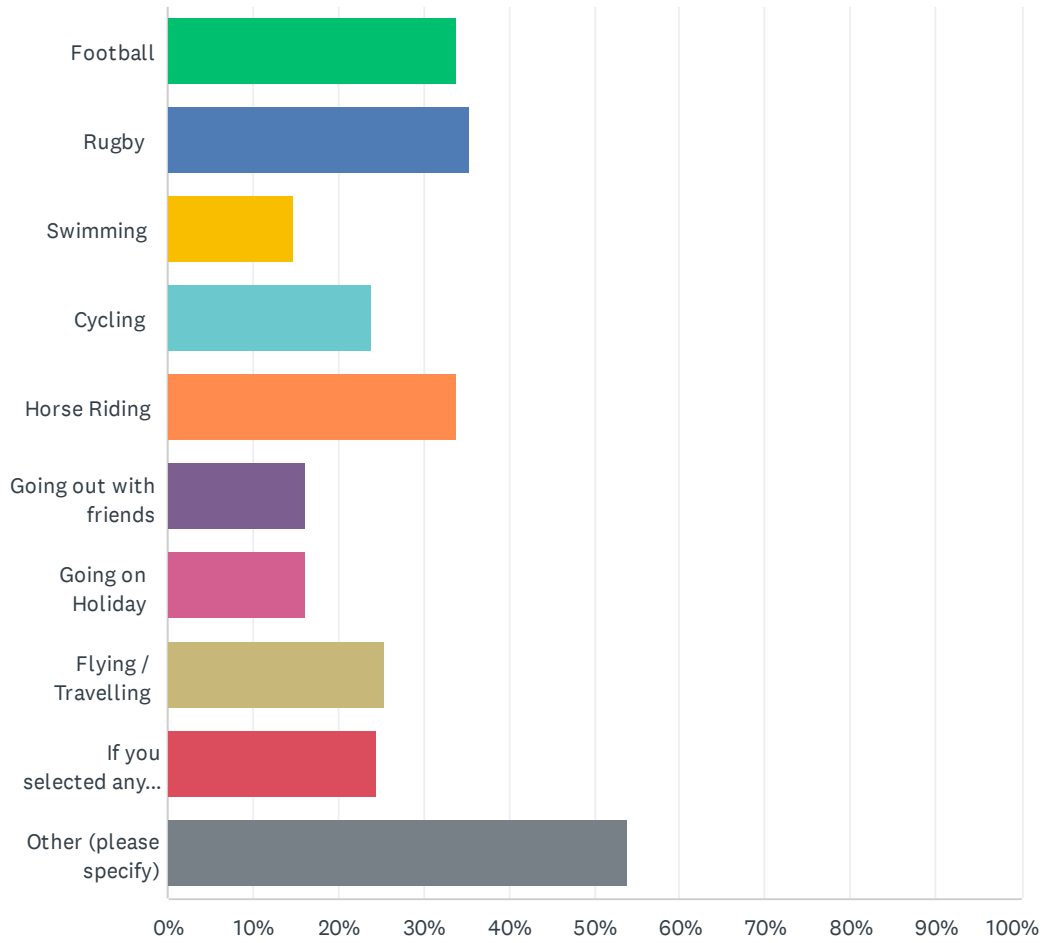


ITP Support Association Patient Perception Survey 2020

ANSWER CHOICES	RESPONSES	
Steroid (Prednisolone, Methylprednisolone, Dexamethasone)	86.81%	158
Intravenous Immunoglobulin (Ivig)	47.25%	86
Anti-D	6.04%	11
Rituximab	41.21%	75
Danazol	4.40%	8
Dapsone	2.20%	4
Azathioprine	17.58%	32
Cyclophosphamide	2.75%	5
Vincristine or Vinblastine	3.85%	7
Cyclosporine	5.49%	10
Platelet Transfusion	18.68%	34
Splenectomy	12.64%	23
Revolade (eltrombopag)	29.67%	54
N plate (Romiplostim)	26.92%	49
Other (please specify)	35.16%	64
Total Respondents: 182		

### Q32 What activities are you unable to do?

Answered: 130 Skipped: 64

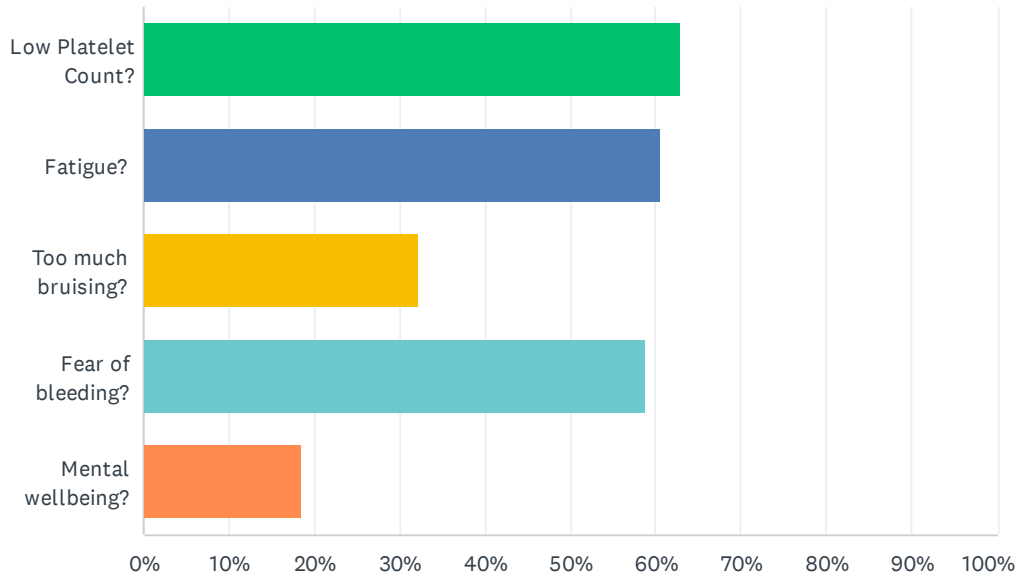


ITP Support Association Patient Perception Survey 2020

ANSWER CHOICES	RESPONSES	
Football	33.85%	44
Rugby	35.38%	46
Swimming	14.62%	19
Cycling	23.85%	31
Horse Riding	33.85%	44
Going out with friends	16.15%	21
Going on Holiday	16.15%	21
Flying / Travelling	25.38%	33
If you selected any of the activities in this question was this under advisement from a Health Care Professional.	24.62%	32
Other (please specify)	53.85%	70
Total Respondents: 130		

### Q33 If you have been unable to do an activity (Q32) Why?

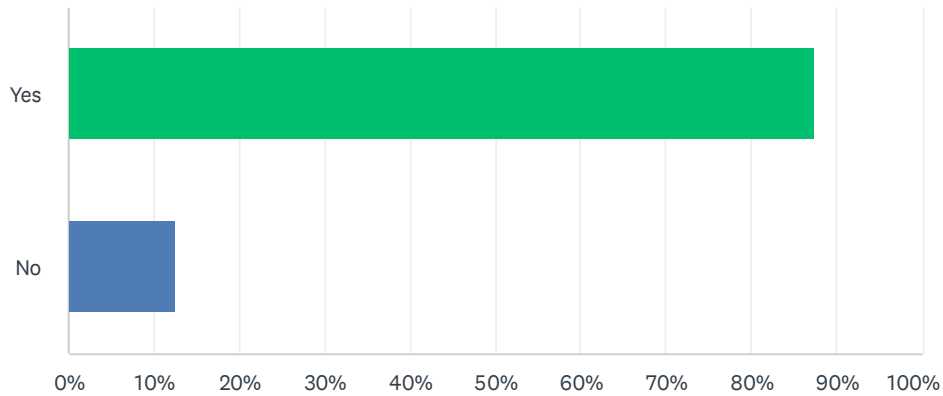
Answered: 124 Skipped: 70



ANSWER CHOICES	RESPONSES	
Low Platelet Count?	62.90%	78
Fatigue?	60.48%	75
Too much bruising?	32.26%	40
Fear of bleeding?	58.87%	73
Mental wellbeing?	18.55%	23
Total Respondents: 124		

Q34 The number of Local ITP Groups is growing but we do not yet cover the whole country, would you be interested in attending a Local Group if one could be established near you?

Answered: 182 Skipped: 12



ANSWER CHOICES	RESPONSES	
Yes	87.36%	159
No	12.64%	23
Total Respondents: 182		

Q35 If you answered Yes to Question 34 please tell us which is your county of residence. This will help us plan for future meetings.

Answered: 157 Skipped: 37

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

Answered: 36 Skipped: 158