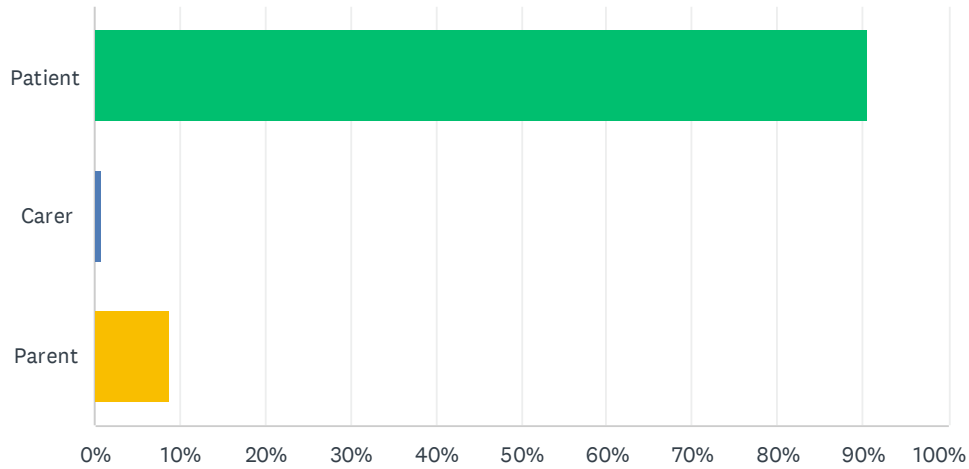


Q1 Are you completing this survey as an ITP patient, carer or the parent of a child with ITP? (Patient / Parent of a Child)

Answered: 329 Skipped: 4



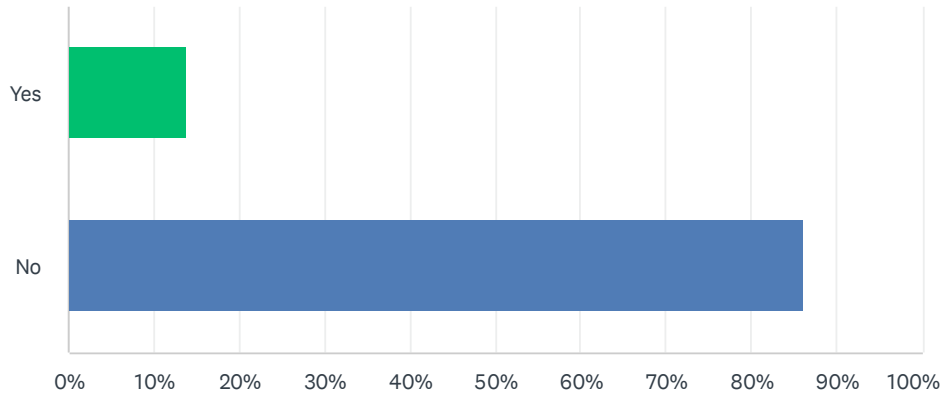
ANSWER CHOICES	RESPONSES	
Patient	90.58%	298
Carer	0.91%	3
Parent	8.81%	29
Total Respondents: 329		

Q2 Your Hospital or ITP Specialist Centre Name:

Answered: 322 Skipped: 11

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

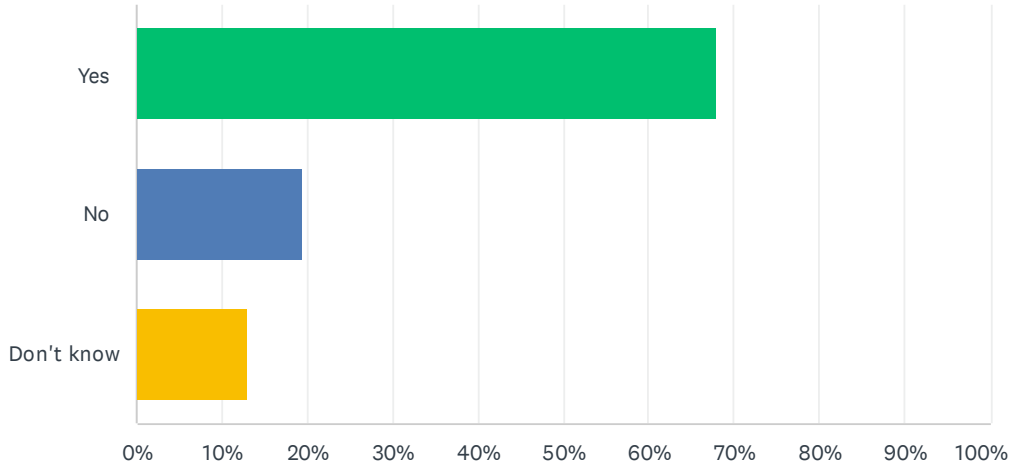
Answered: 327 Skipped: 6



ANSWER CHOICES	RESPONSES	
Yes	13.76%	45
No	86.24%	282
Total Respondents: 327		

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

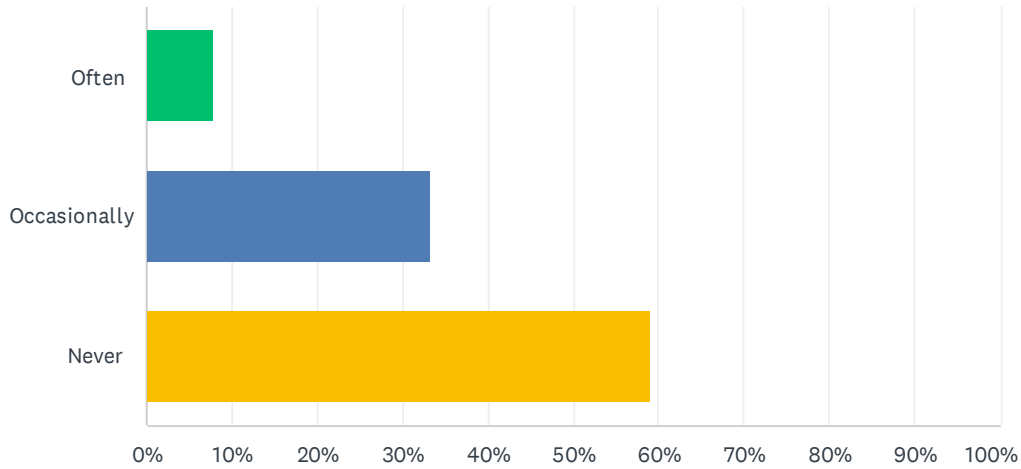
Answered: 331 Skipped: 2



ANSWER CHOICES	RESPONSES	
Yes	67.98%	225
No	19.34%	64
Don't know	12.99%	43
Total Respondents: 331		

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

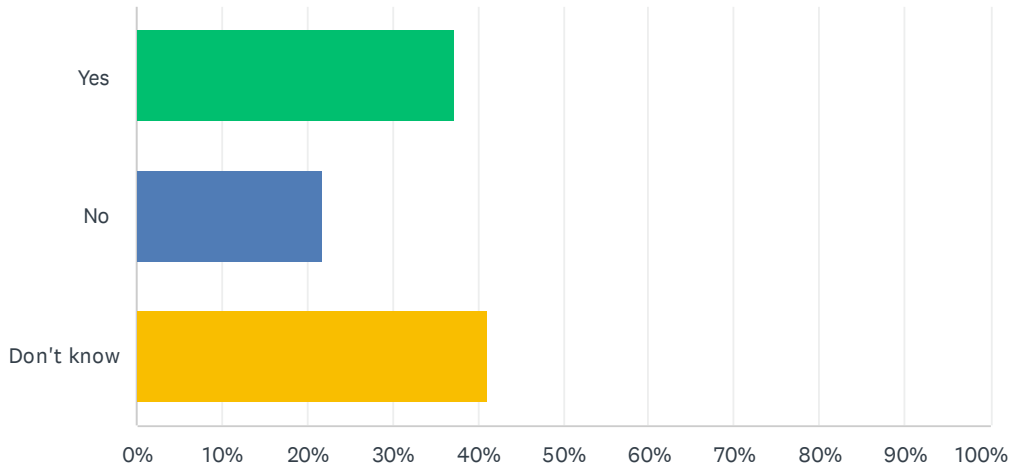
Answered: 328 Skipped: 5



ANSWER CHOICES	RESPONSES
Often	7.93% 26
Occasionally	33.23% 109
Never	59.15% 194
Total Respondents: 328	

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

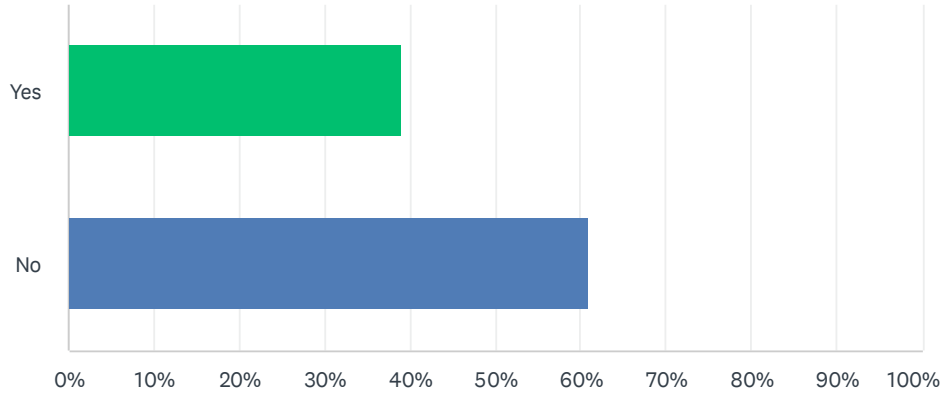
Answered: 330 Skipped: 3



ANSWER CHOICES	RESPONSES	
Yes	37.27%	123
No	21.82%	72
Don't know	41.21%	136
Total Respondents: 330		

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

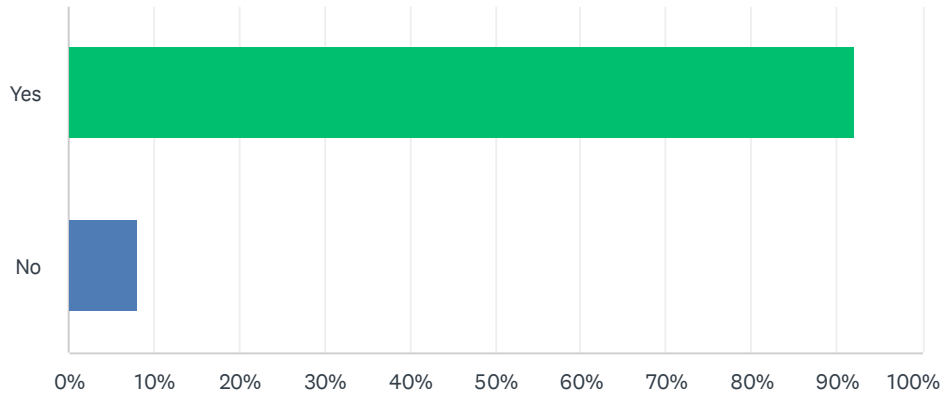
Answered: 315 Skipped: 18



ANSWER CHOICES	RESPONSES	
Yes	39.05%	123
No	60.95%	192
Total Respondents: 315		

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

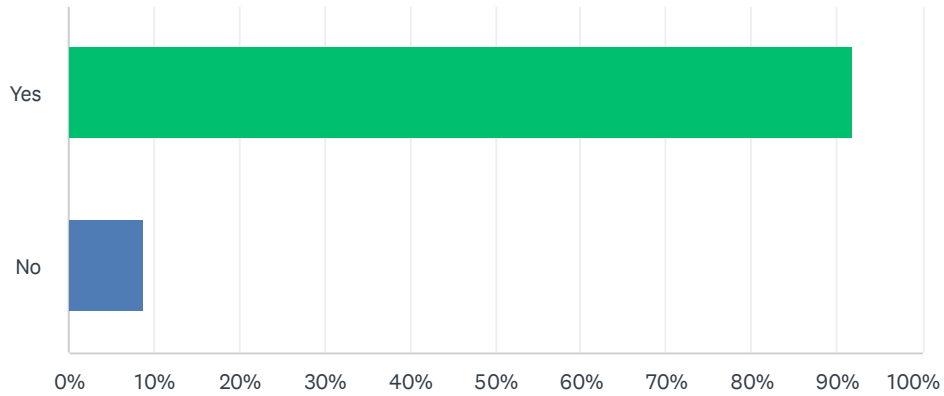
Answered: 329 Skipped: 4



ANSWER CHOICES	RESPONSES	
Yes	92.10%	303
No	8.21%	27
Total Respondents: 329		

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

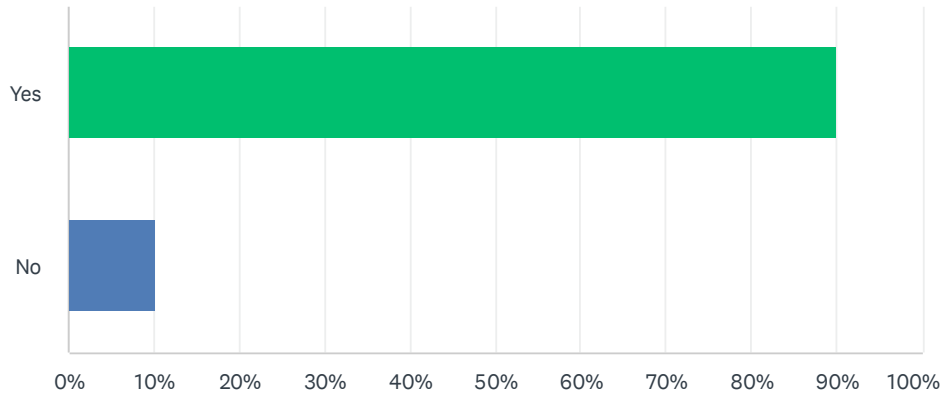
Answered: 329 Skipped: 4



ANSWER CHOICES	RESPONSES	
Yes	91.79%	302
No	8.81%	29
Total Respondents: 329		

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

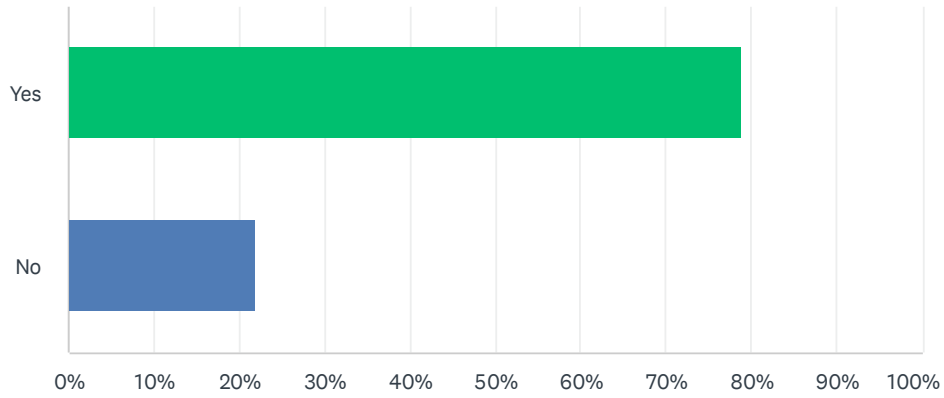
Answered: 329 Skipped: 4



ANSWER CHOICES	RESPONSES	
Yes	89.97%	296
No	10.33%	34
Total Respondents: 329		

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: 322 Skipped: 11



ANSWER CHOICES	RESPONSES	
Yes	78.88%	254
No	22.05%	71
Total Respondents: 322		

**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.**

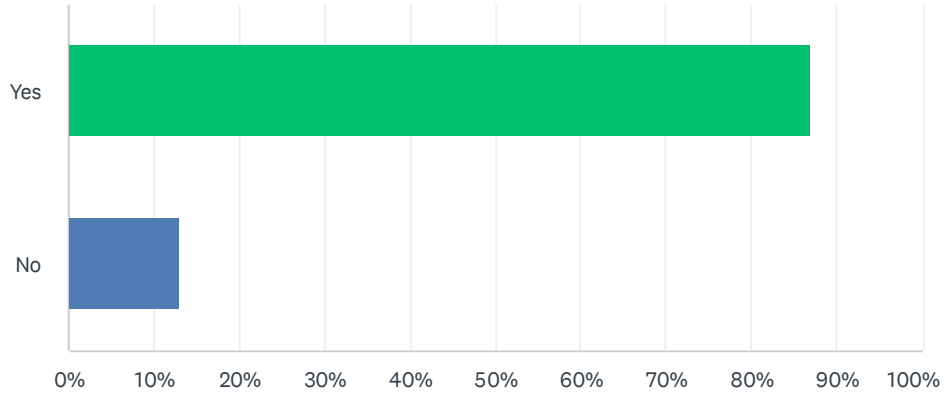
Answered: 316 Skipped: 17

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

Answered: 319 Skipped: 14

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

Answered: 317 Skipped: 16



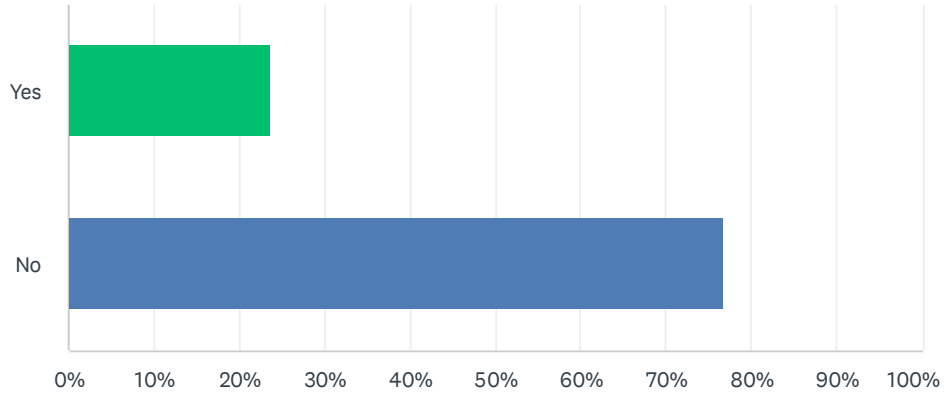
ANSWER CHOICES	RESPONSES	
Yes	87.07%	276
No	12.93%	41
Total Respondents: 317		

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

Answered: 308 Skipped: 25

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

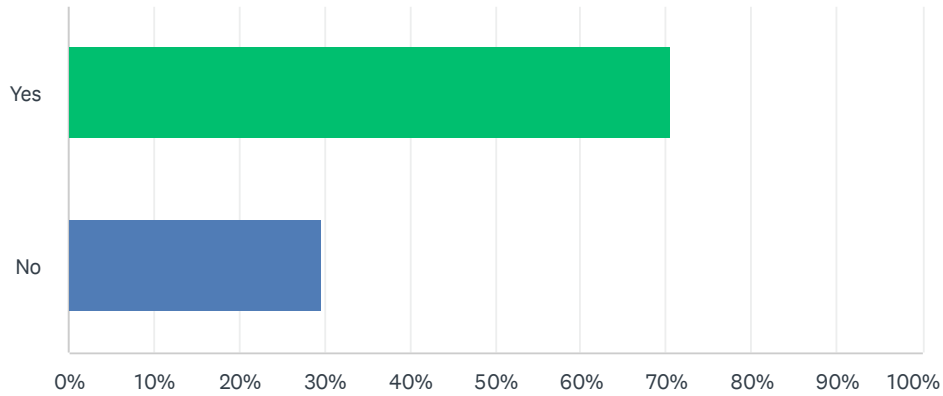
Answered: 330 Skipped: 3



ANSWER CHOICES	RESPONSES	
Yes	23.64%	78
No	76.67%	253
Total Respondents: 330		

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

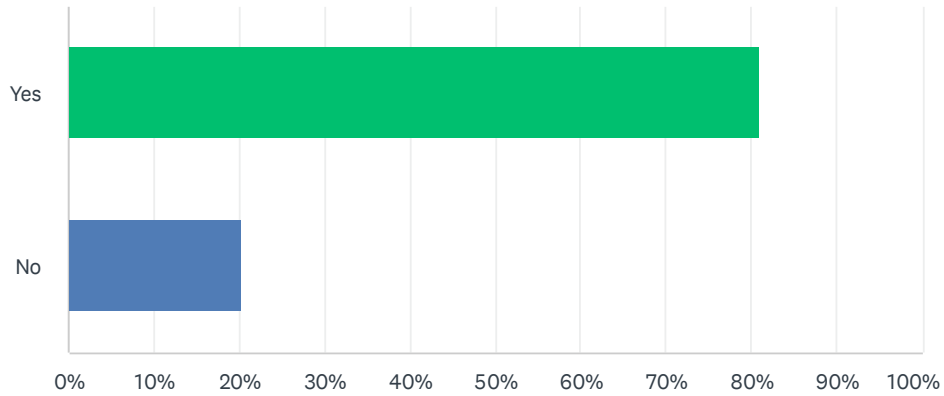
Answered: 330 Skipped: 3



ANSWER CHOICES	RESPONSES	
Yes	70.61%	233
No	29.70%	98
Total Respondents: 330		

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

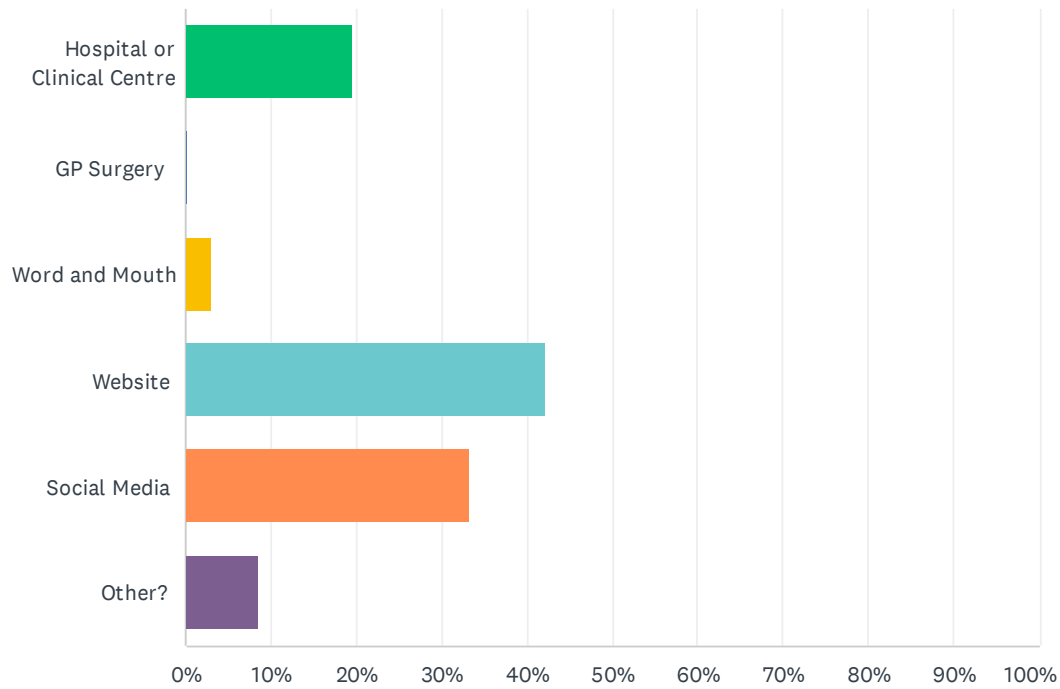
Answered: 325 Skipped: 8



ANSWER CHOICES	RESPONSES	
Yes	80.92%	263
No	20.31%	66
Total Respondents: 325		

Q19 Where did you hear about the ITP Support Association?

Answered: 331 Skipped: 2



ANSWER CHOICES	RESPONSES	
Hospital or Clinical Centre	19.64%	65
GP Surgery	0.30%	1
Word and Mouth	3.02%	10
Website	42.30%	140
Social Media	33.23%	110
Other?	8.46%	28
Total Respondents: 331		

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: 98 Skipped: 235

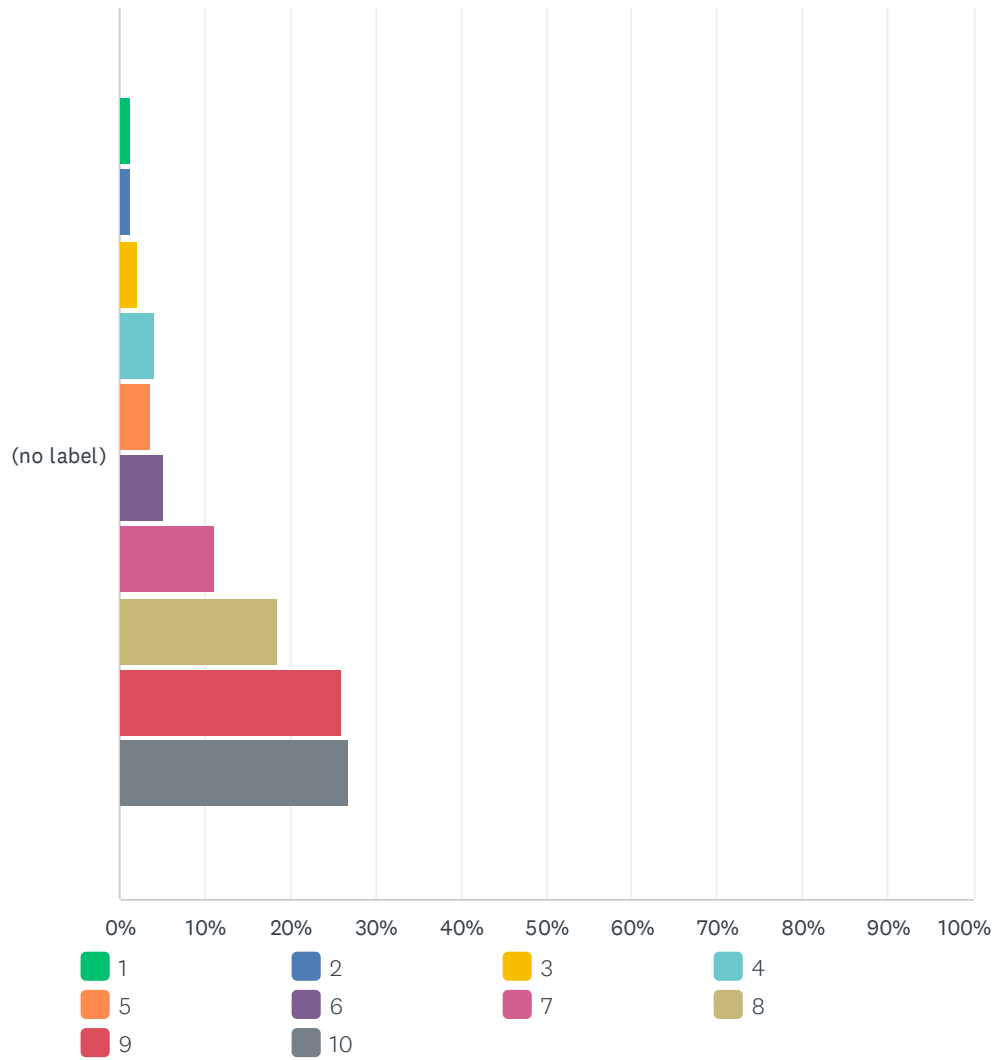
ANSWER CHOICES	RESPONSES	
1	100.00%	98
2	76.53%	75
3	65.31%	64

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

Answered: 196 Skipped: 137

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.

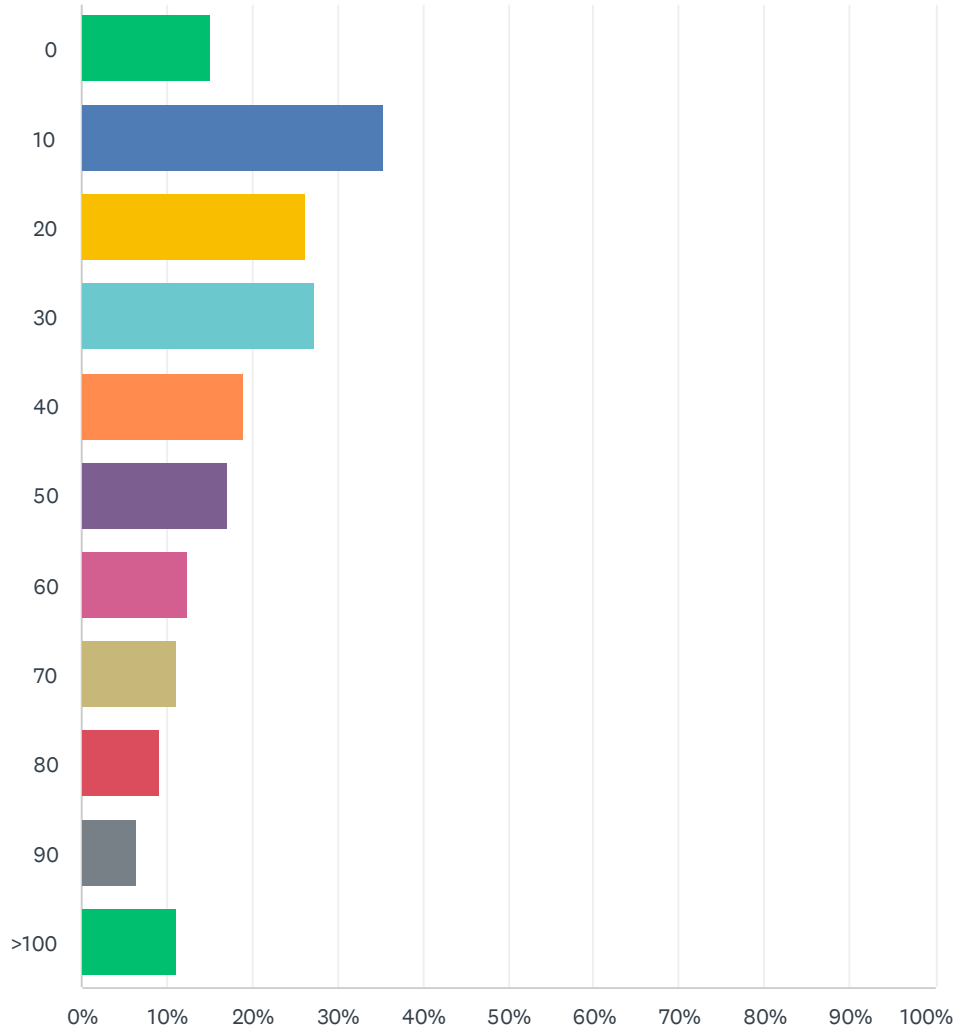
Answered: 327 Skipped: 6



	1	2	3	4	5	6	7	8	9	10	TOTAL	WEIGHTED AVERAGE
(no label)	1.22% 4	1.22% 4	2.14% 7	3.98% 13	3.67% 12	5.20% 17	11.01% 36	18.65% 61	25.99% 85	26.91% 88	327	8.05

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: 252 Skipped: 81



ITP Support Association Patient Perception Survey 2022

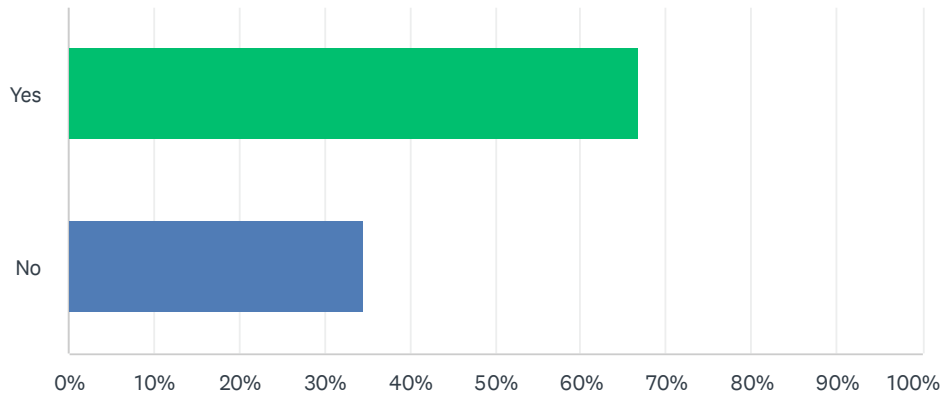
ANSWER CHOICES	RESPONSES	
0	15.08%	38
10	35.32%	89
20	26.19%	66
30	27.38%	69
40	19.05%	48
50	17.06%	43
60	12.30%	31
70	11.11%	28
80	9.13%	23
90	6.35%	16
>100	11.11%	28
Total Respondents: 252		

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: 311 Skipped: 22

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: 324 Skipped: 9



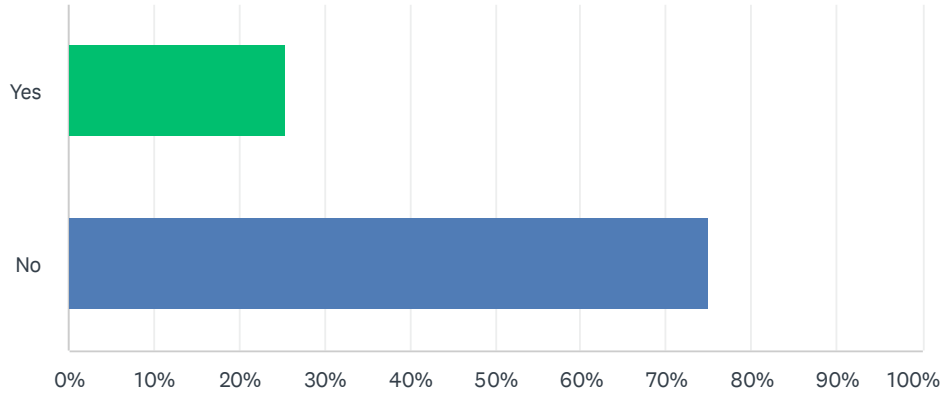
ANSWER CHOICES	RESPONSES	
Yes	66.67%	216
No	34.57%	112
Total Respondents: 324		

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

Answered: 219 Skipped: 114

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

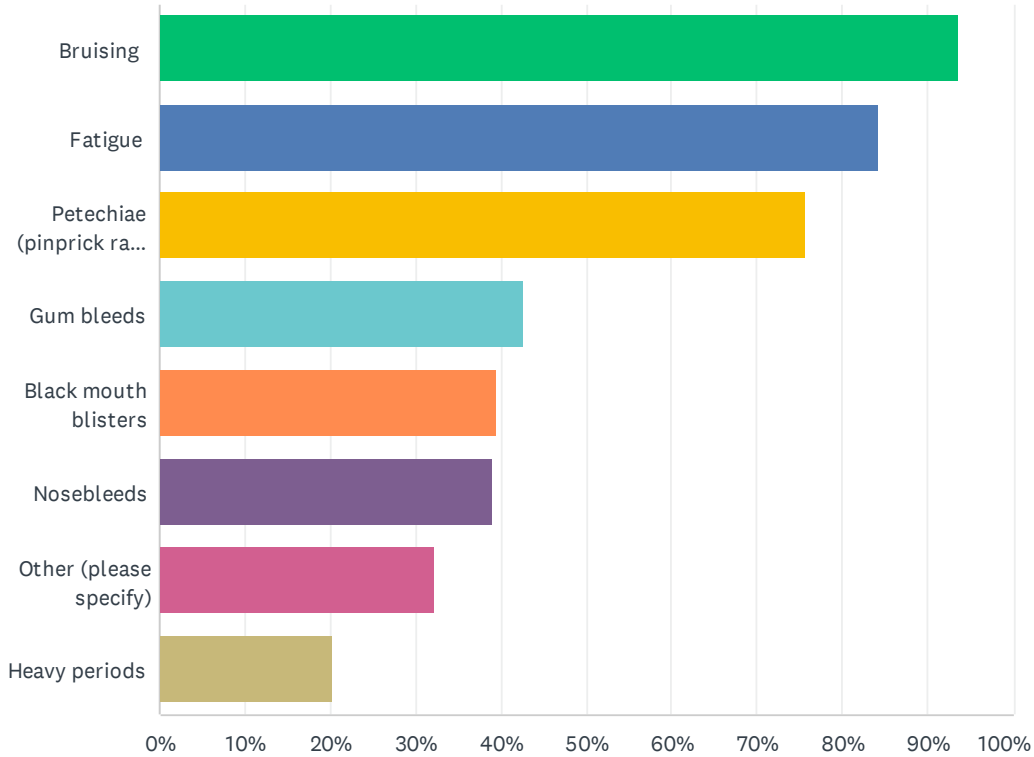
Answered: 224 Skipped: 109



ANSWER CHOICES	RESPONSES	
Yes	25.45%	57
No	75.00%	168
Total Respondents: 224		

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

Answered: 330 Skipped: 3

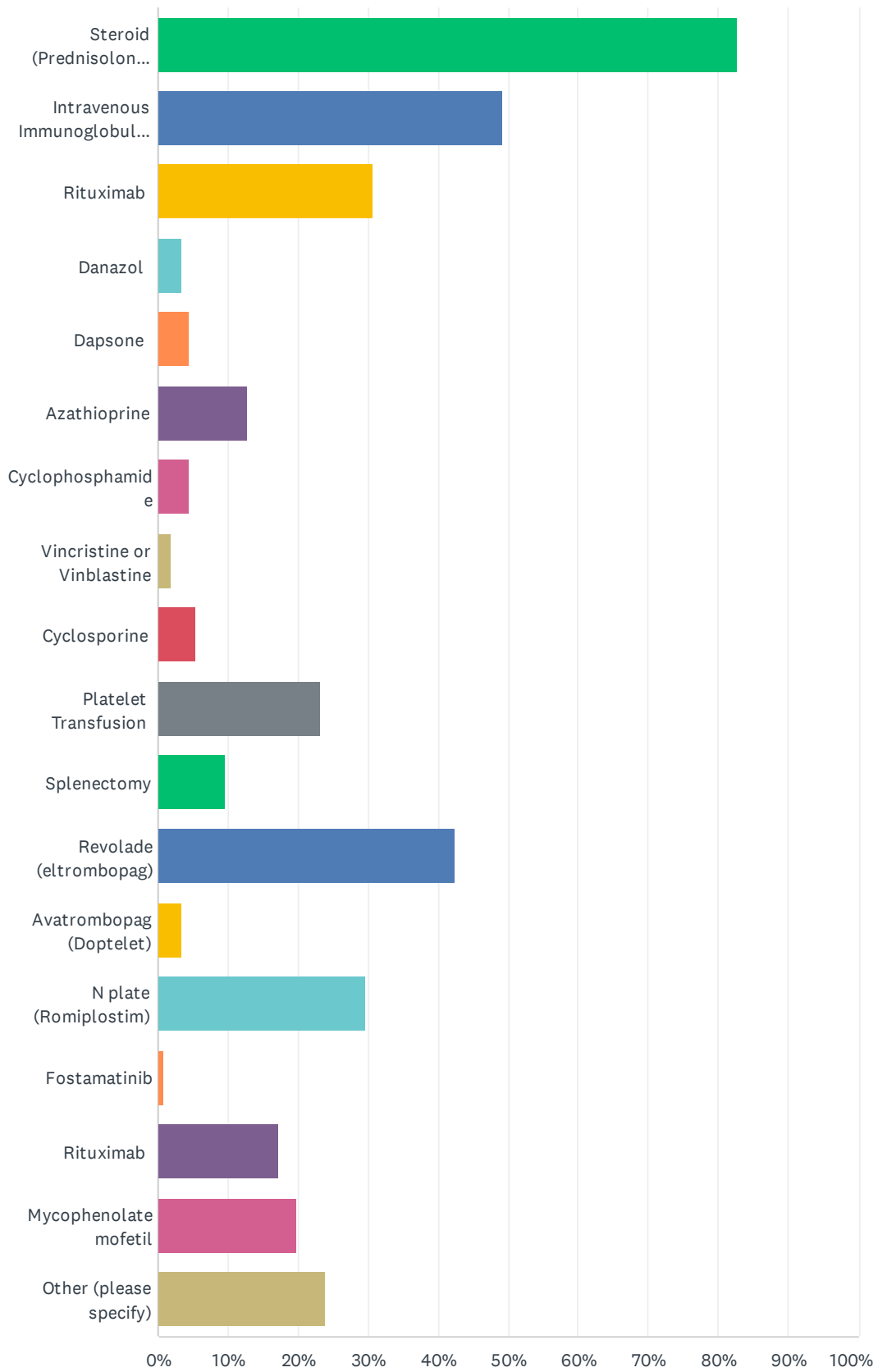


ANSWER CHOICES	RESPONSES	
Bruising	93.64%	309
Fatigue	84.24%	278
Petechiae (pinprick rash of blood spots)	75.76%	250
Gum bleeds	42.73%	141
Black mouth blisters	39.39%	130
Nosebleeds	39.09%	129
Other (please specify)	32.12%	106
Heavy periods	20.30%	67
Total Respondents: 330		

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

Answered: 313 Skipped: 20

ITP Support Association Patient Perception Survey 2022

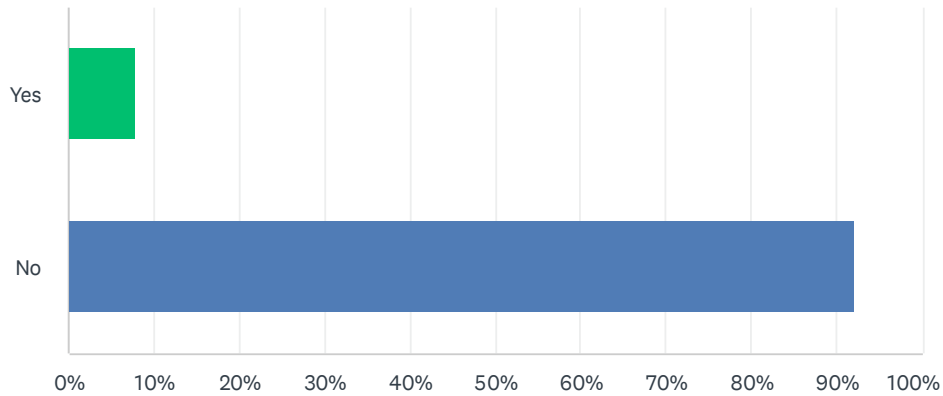


ITP Support Association Patient Perception Survey 2022

ANSWER CHOICES	RESPONSES	
Steroid (Prednisolone, Methylprednisolone, Dexamethasone)	82.75%	259
Intravenous Immunoglobulin (Ivlg)	49.20%	154
Rituximab	30.67%	96
Danazol	3.51%	11
Dapsone	4.47%	14
Azathioprine	12.78%	40
Cyclophosphamide	4.47%	14
Vincristine or Vinblastine	1.92%	6
Cyclosporine	5.43%	17
Platelet Transfusion	23.32%	73
Splenectomy	9.58%	30
Revolade (eltrombopag)	42.49%	133
Avatrombopag (Doptelet)	3.51%	11
N plate (Romiplostim)	29.71%	93
Fostamatinib	0.96%	3
Rituximab	17.25%	54
Mycophenolate mofetil	19.81%	62
Other (please specify)	23.96%	75
Total Respondents: 313		

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: 295 Skipped: 38



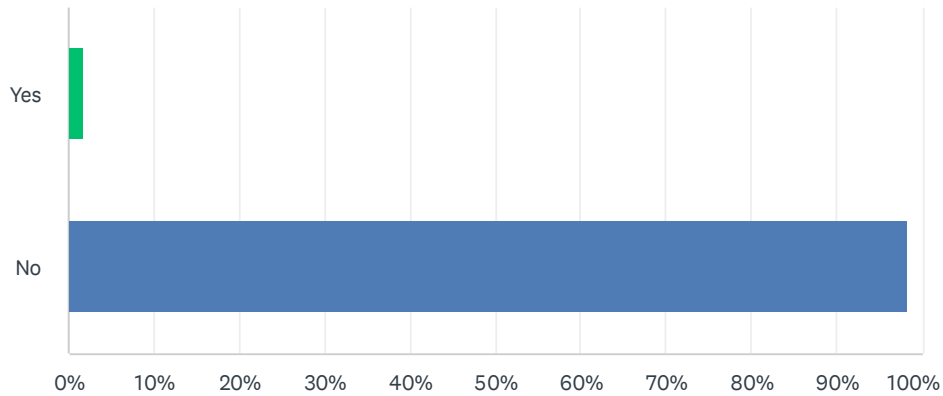
ANSWER CHOICES	RESPONSES
Yes	7.80% 23
No	92.20% 272
TOTAL	295

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

Answered: 37 Skipped: 296

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: 287 Skipped: 46



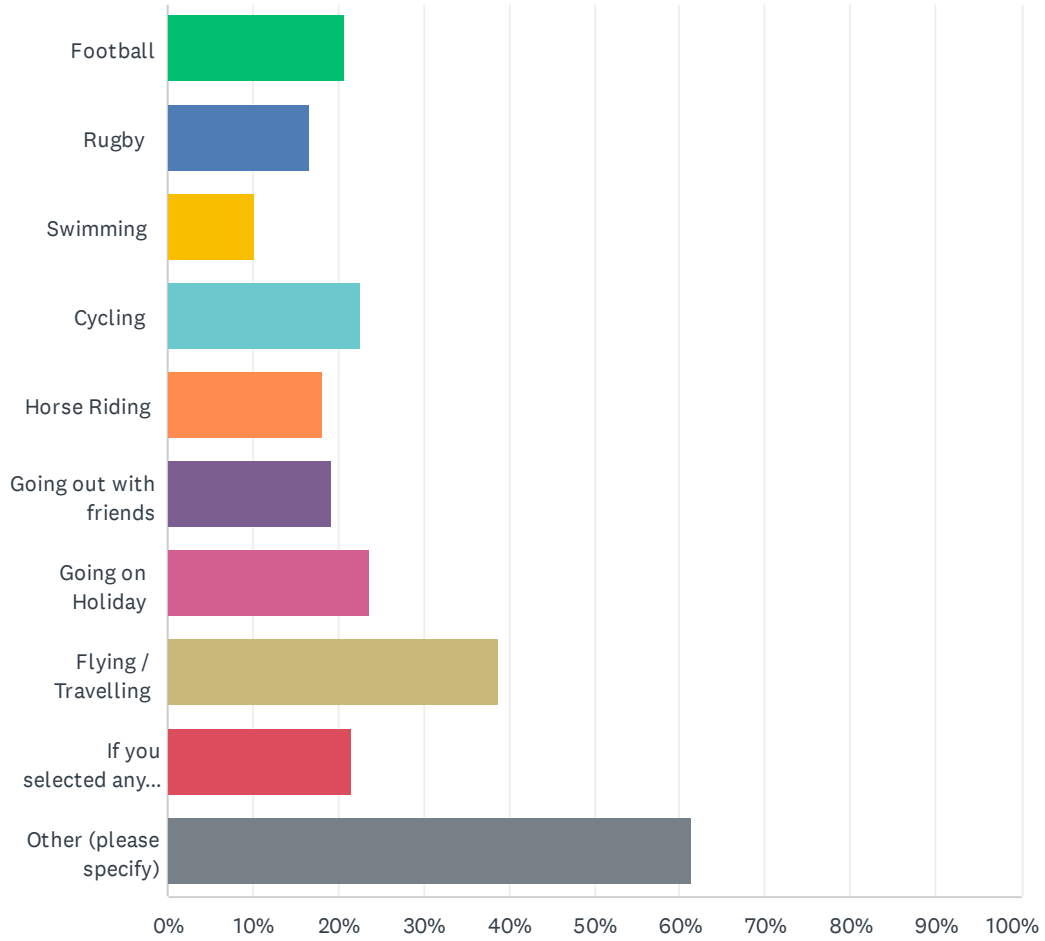
ANSWER CHOICES	RESPONSES
Yes	1.74% 5
No	98.26% 282
TOTAL	287

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: 103 Skipped: 230

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

Answered: 265 Skipped: 68

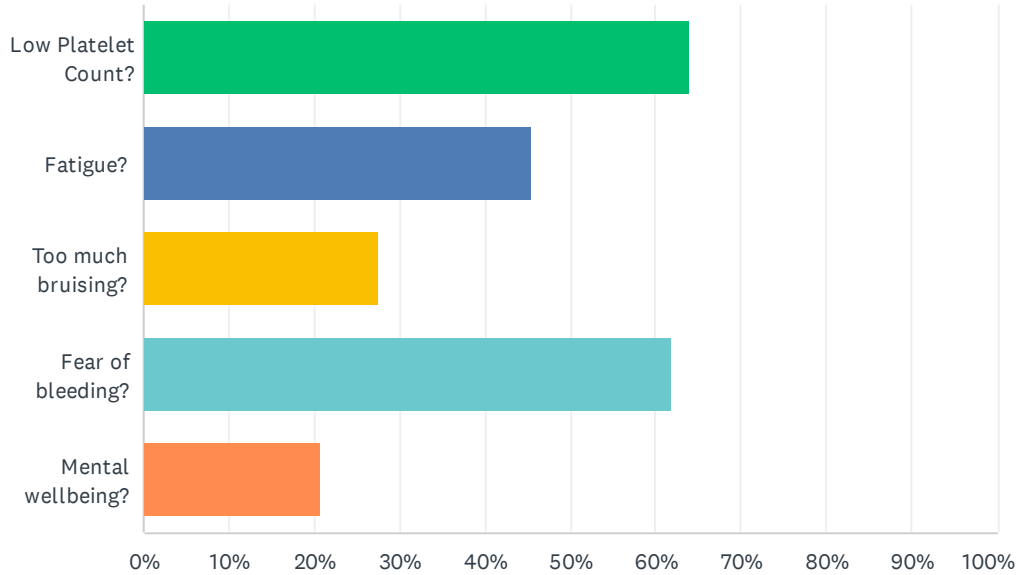


ITP Support Association Patient Perception Survey 2022

ANSWER CHOICES	RESPONSES	
Football	20.75%	55
Rugby	16.60%	44
Swimming	10.19%	27
Cycling	22.64%	60
Horse Riding	18.11%	48
Going out with friends	19.25%	51
Going on Holiday	23.77%	63
Flying / Travelling	38.87%	103
If you selected any of the activities in this question was this under advisement from a Health Care Professional.	21.51%	57
Other (please specify)	61.51%	163
Total Respondents: 265		

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

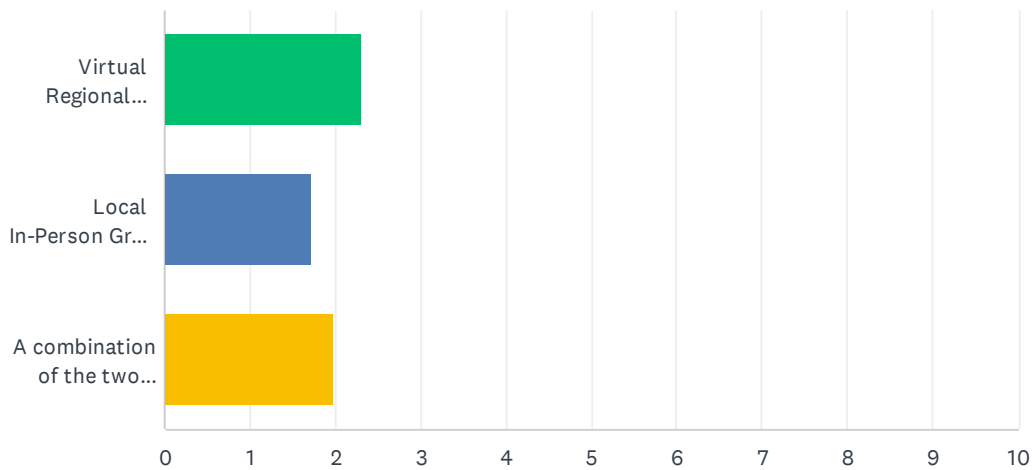
Answered: 233 Skipped: 100



ANSWER CHOICES	RESPONSES	
Low Platelet Count?	63.95%	149
Fatigue?	45.49%	106
Too much bruising?	27.47%	64
Fear of bleeding?	61.80%	144
Mental wellbeing?	20.60%	48
Total Respondents: 233		

Q36 Pre-Covid we held a number of in-person Local ITP Groups around the UK. During Covid we also held Regional Virtual Support Group meeting with a Medical Advisor taking part. In order to help us plan for the future would you prefer remaining with the Virtual Regional Group Meetings (with a medical advisor) or going back to the local in-person group meetings (without a medical advisor). Or a combination of the two? Please rank your preference below.

Answered: 282 Skipped: 51



	1	2	3	TOTAL	SCORE
Virtual Regional Meetings (with a medical advisor)	51.71% 136	27.38% 72	20.91% 55	263	2.31
Local In-Person Group Meetings (without a medical advisor)	20.32% 51	31.87% 80	47.81% 120	251	1.73
A combination of the two Regional and Local	29.96% 80	38.95% 104	31.09% 83	267	1.99

Q37 If you preferred a local in-person support group in Question 36 please tell us which is your county of residence. This will help us plan for future meetings.

Answered: 155 Skipped: 178

Q38 If you have any points you would like included in future surveys please provide the details here.

Answered: 43 Skipped: 290

Q39 Please provide your Postal Code

Answered: 317 Skipped: 16