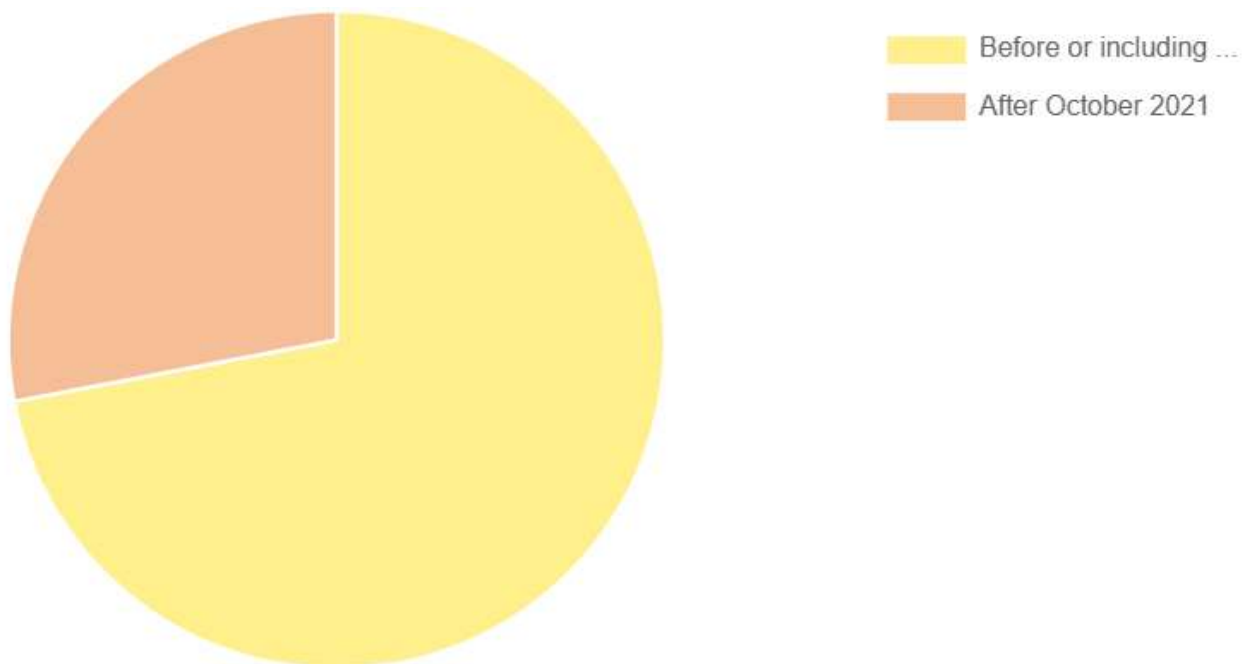


Website Survey: Requesting information about your ME/CFS Diagnosis

Question 1 ☰ MULTIPLE CHOICE

Were you diagnosed with ME/CFS in the UK before October 2021 (publication of the updated NICE Guideline) or after October 2021?



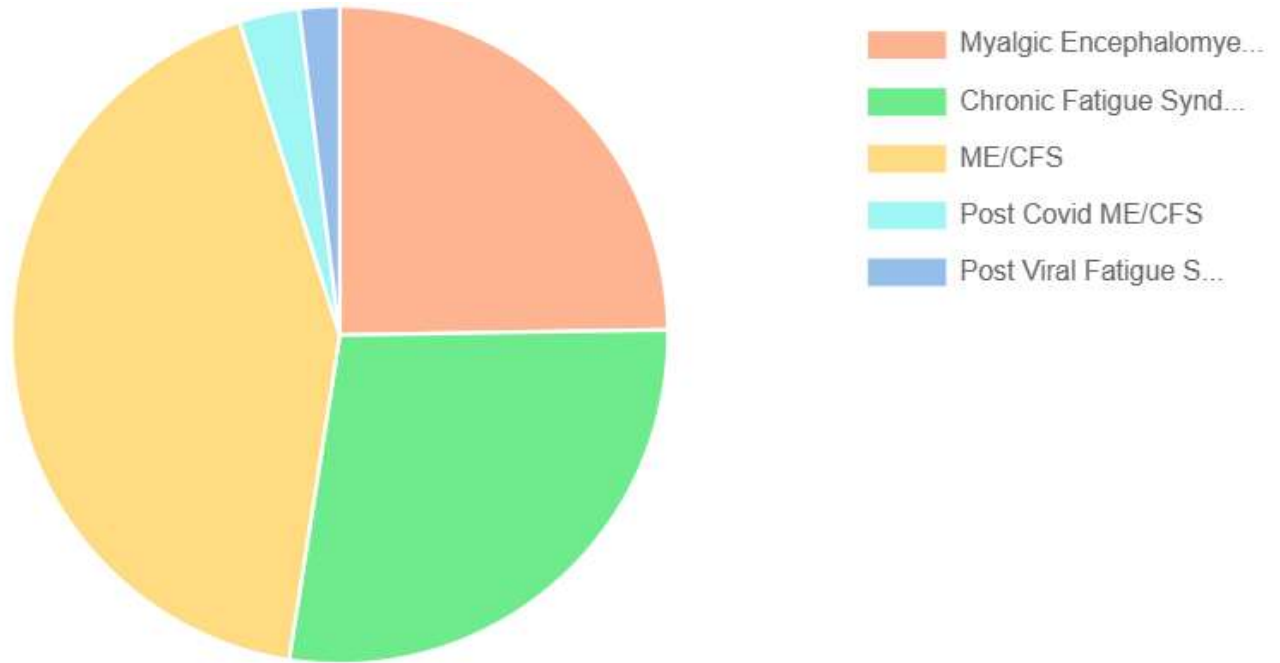
ANSWERS	RESPONSES
Before or including October 2021	72% 612
After October 2021	28% 234

846 Answered

0 Skipped

Question 2 ☰ MULTIPLE CHOICE

What diagnosis have you been given?



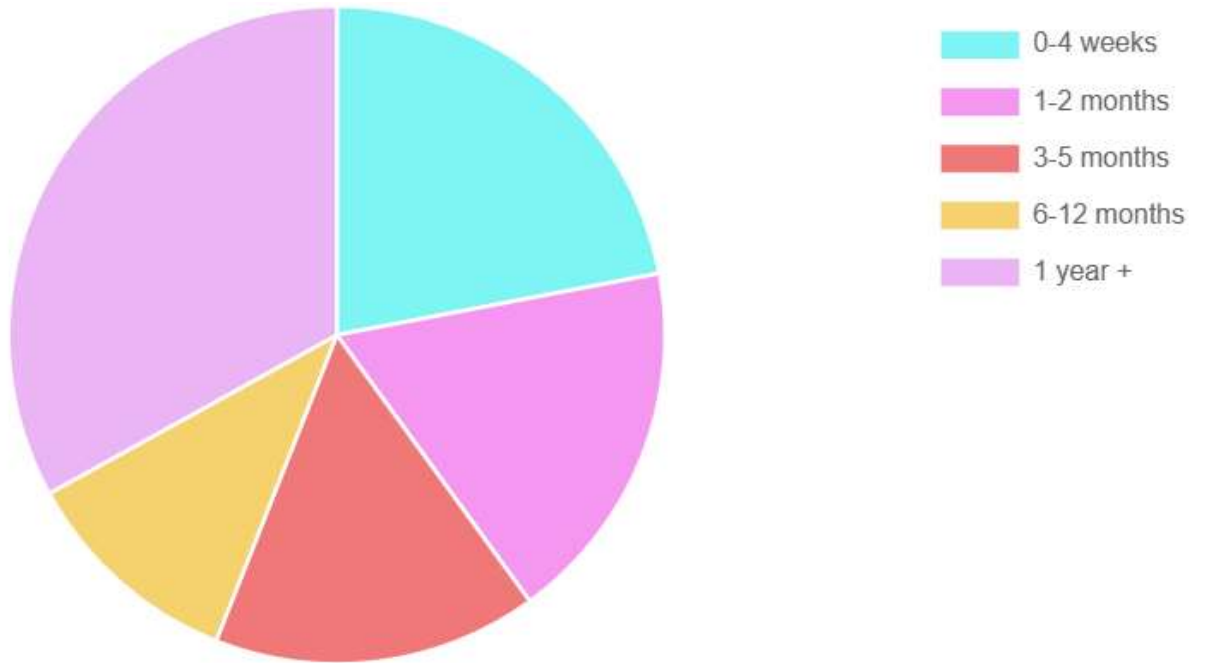
ANSWERS	RESPONSES	
ME/CFS	43%	360
Myalgic Encephalomyelitis (ME)	25%	209
Chronic Fatigue Syndrome (CFS)	28%	234
Post Covid ME/CFS	3%	24
Post Viral Fatigue Syndrome (PVFS)	2%	19

846 Answered

0 Skipped

Question 3 ☰ MULTIPLE CHOICE

How long did you experience symptoms before visiting your GP?



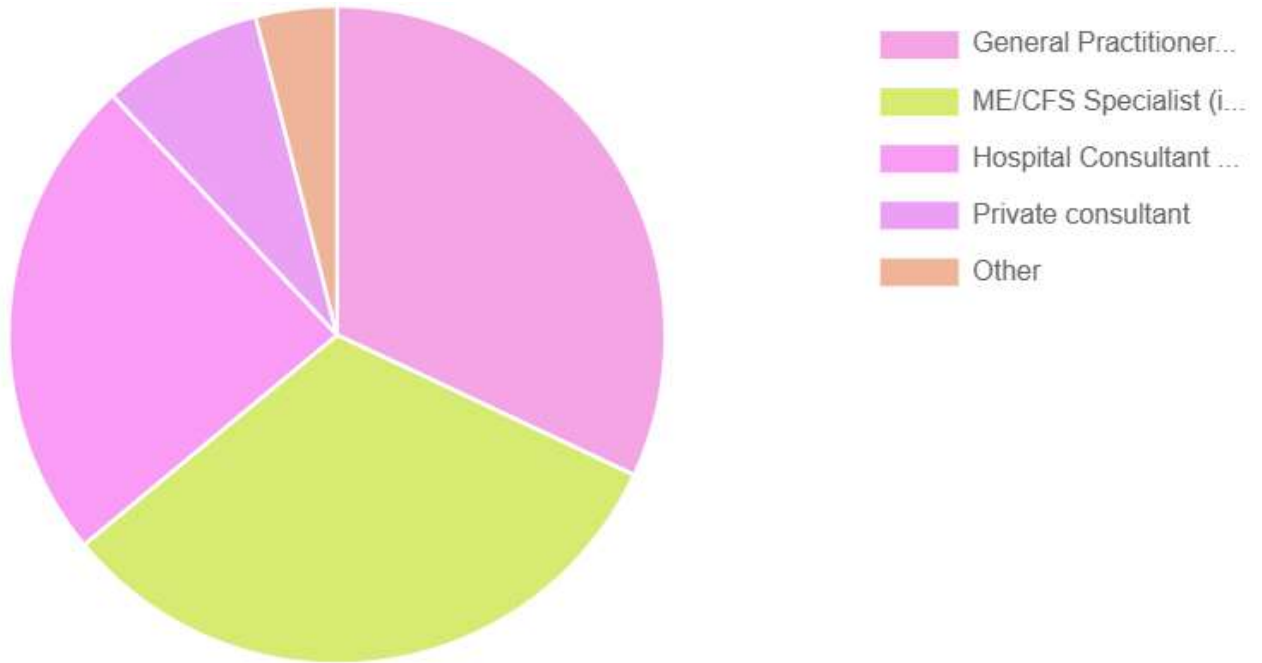
ANSWERS	RESPONSES	
0-4 weeks	22%	186
1 year +	33%	281
3-5 months	16%	138
6-12 months	11%	91
1-2 months	18%	150

846 Answered

0 Skipped

Question 4 ☰ MULTIPLE CHOICE

Who made the diagnosis of ME/CFS?



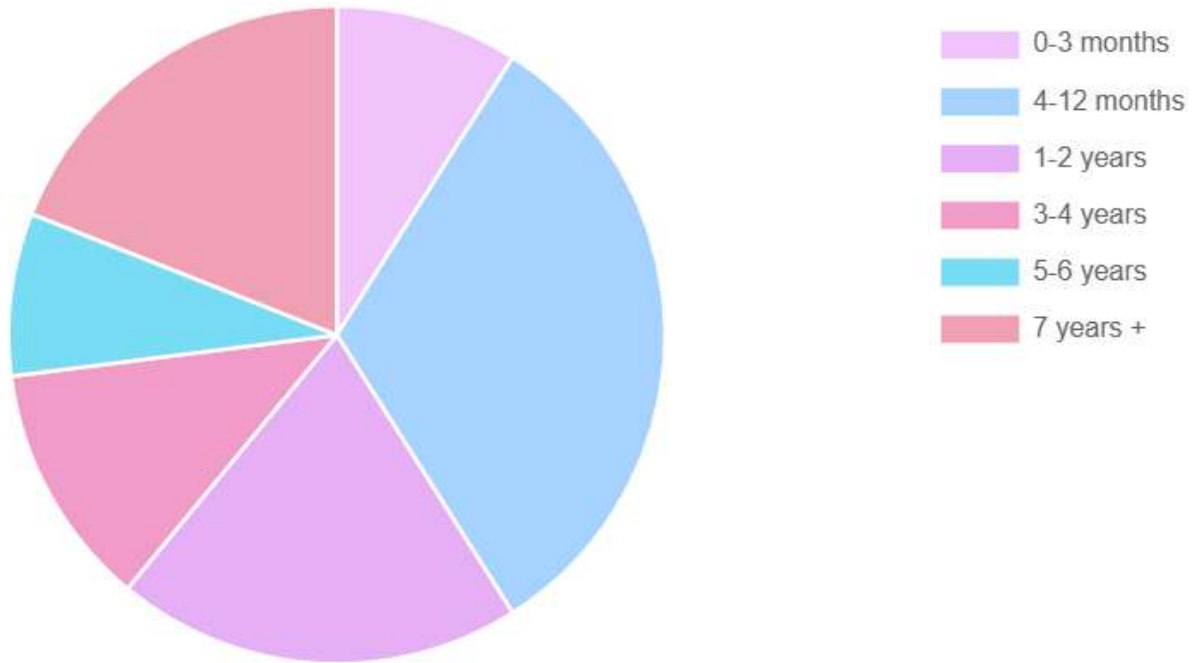
ANSWERS	RESPONSES	
General Practitioner (i.e. Primary Care)	32%	270
ME/CFS Specialist (i.e. Secondary care)	32%	273
Hospital Consultant (Rheumatologist, Neurologist etc)	24%	205
Other	4%	32
Private consultant	8%	66

846 Answered

0 Skipped

Question 6 ☰ MULTIPLE CHOICE

(Before NICE guideline update): How long did it take to get an accurate diagnosis?



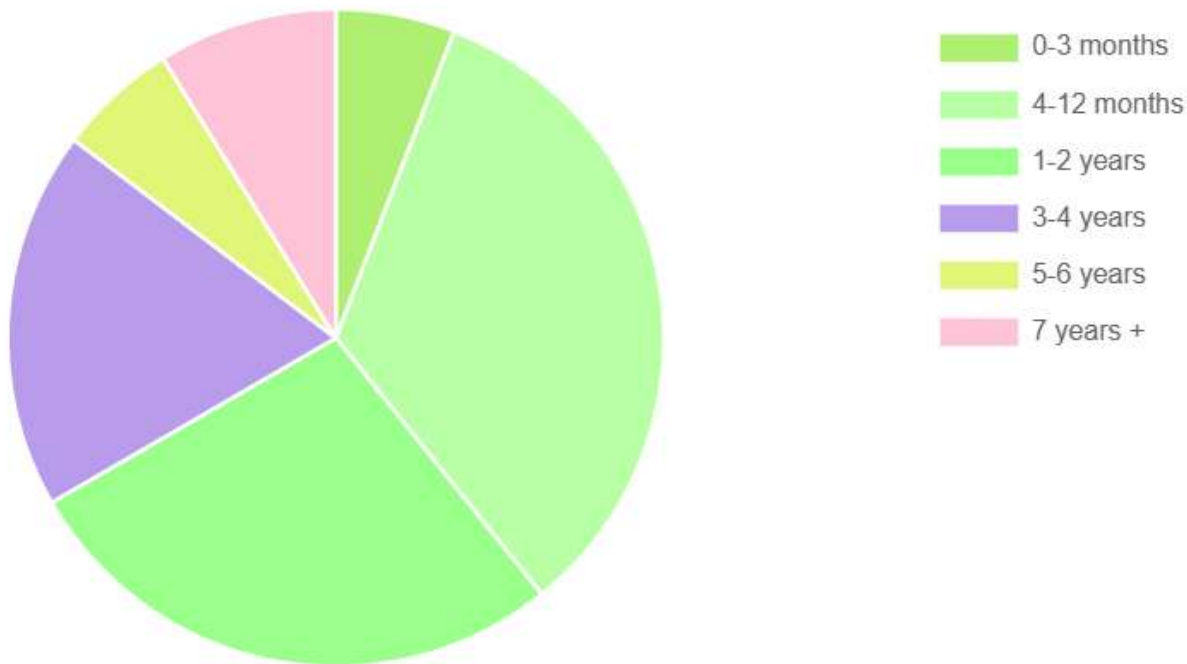
ANSWERS	RESPONSES	
4-12 months	32%	193
1-2 years	20%	124
5-6 years	8%	48
0-3 months	9%	56
3-4 years	12%	73
7 years +	19%	118

612 Answered

234 Skipped

Question 7 ☰ MULTIPLE CHOICE

(After NICE guideline update): How long did it take to get an accurate diagnosis?



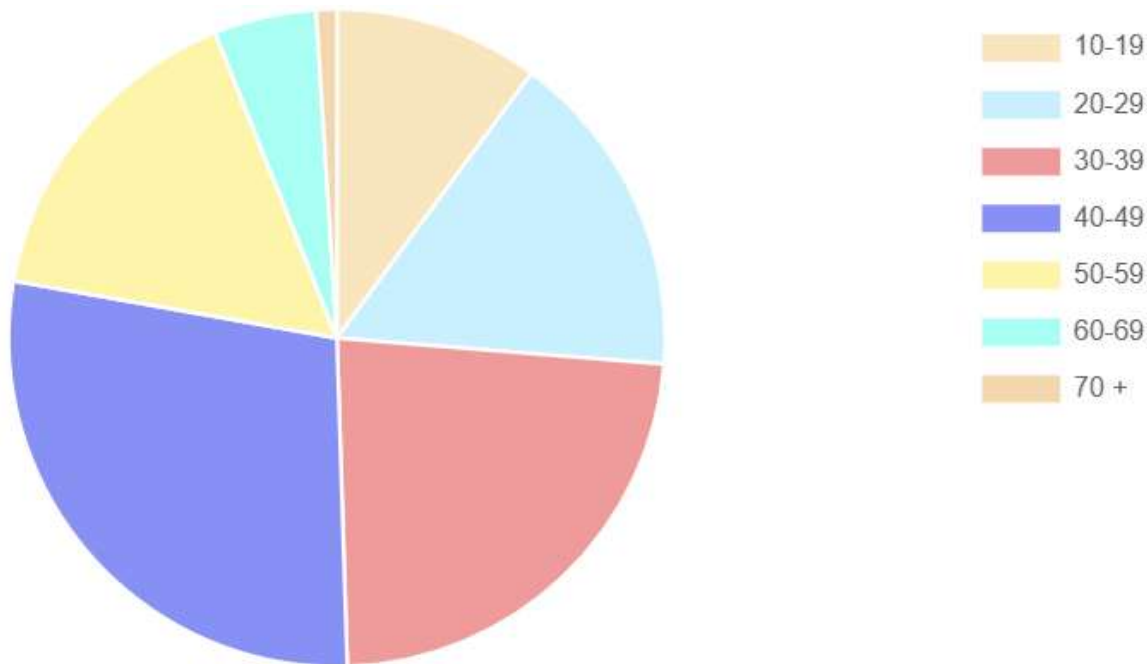
ANSWERS	RESPONSES	
1-2 years	28%	65
7 years +	9%	20
4-12 months	34%	79
3-4 years	19%	44
0-3 months	6%	13
5-6 years	6%	13

234 Answered

612 Skipped

Question 8 ☰ MULTIPLE CHOICE

(Before NICE guideline update): At what age were you diagnosed?



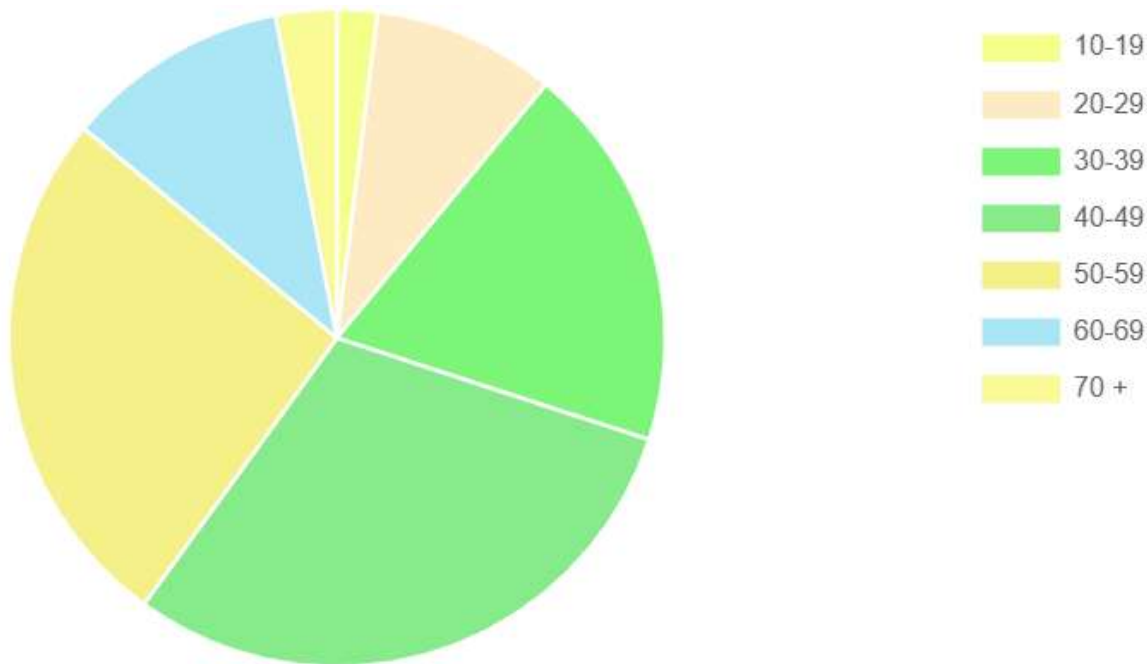
ANSWERS	RESPONSES	
30-39	23%	143
10-19	10%	62
20-29	16%	99
40-49	28%	174
50-59	16%	98
70 +	1%	7
60-69	5%	29

612 Answered

234 Skipped

Question 9 ☰ MULTIPLE CHOICE

(After NICE guideline update): At what age were you diagnosed?



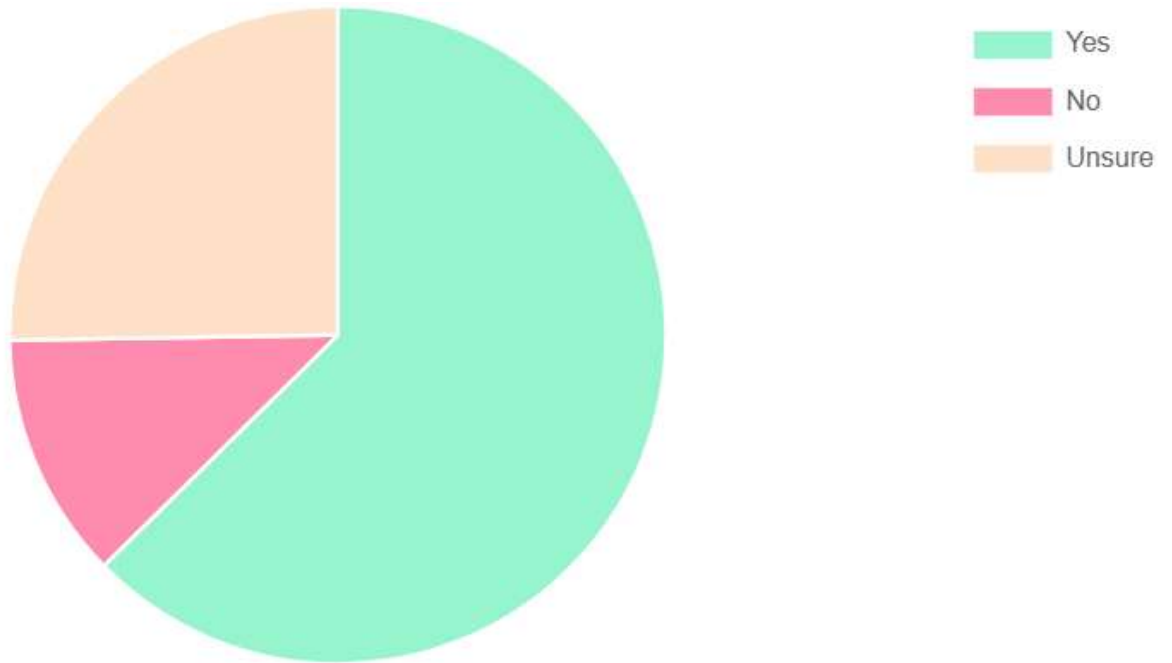
ANSWERS	RESPONSES	
40-49	30%	71
30-39	19%	44
50-59	26%	60
60-69	11%	25
20-29	9%	21
70 +	3%	8
10-19	2%	5

234 Answered

612 Skipped

Question 10 ☰ MULTIPLE CHOICE

Have you had all the blood and urine tests that the NICE guideline recommends to exclude other possible causes of ME/CFS symptoms?



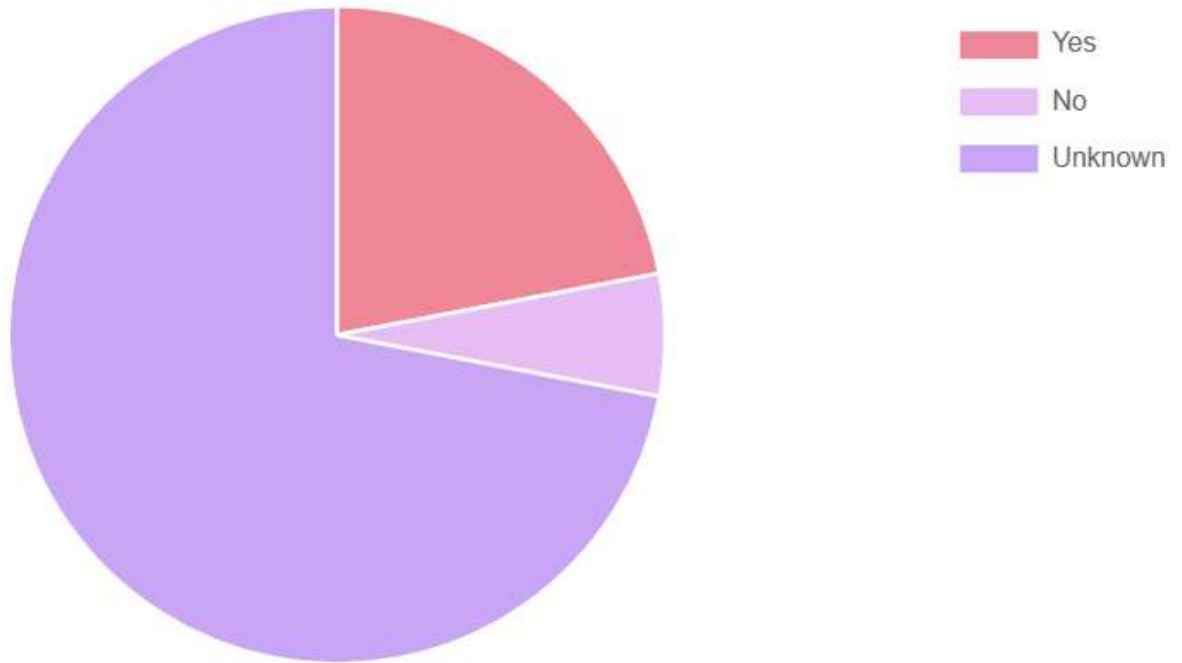
ANSWERS	RESPONSES	
Yes	62%	146
Unsure	25%	59
No	12%	29

234 Answered

612 Skipped

Question 11 ☰ MULTIPLE CHOICE

Was the doctor diagnosing you aware of the 2021 updated NICE Guideline on ME/CFS?



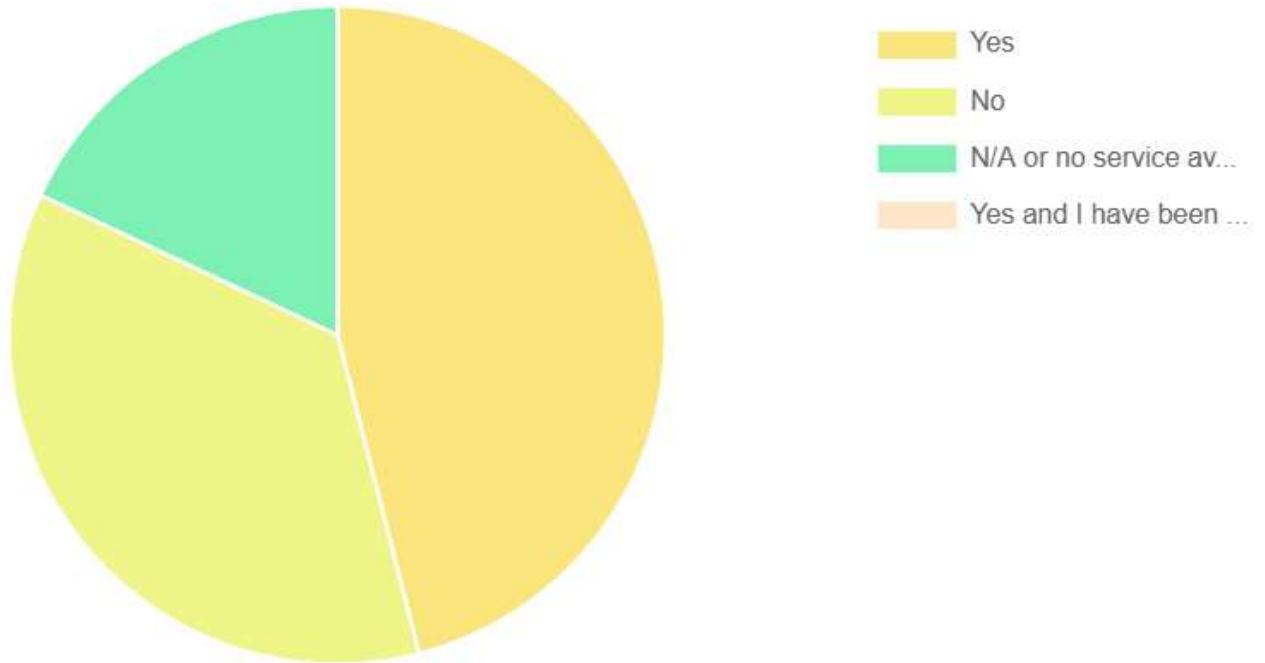
ANSWERS	RESPONSES	
Unknown	72%	168
Yes	22%	51
No	6%	15

234 Answered

612 Skipped

Question 12 ☰ MULTIPLE CHOICE

(Before NICE guideline update) Were you referred by your GP to a specialist ME/CFS referral service in order to confirm the diagnosis and prepare a care and management plan?



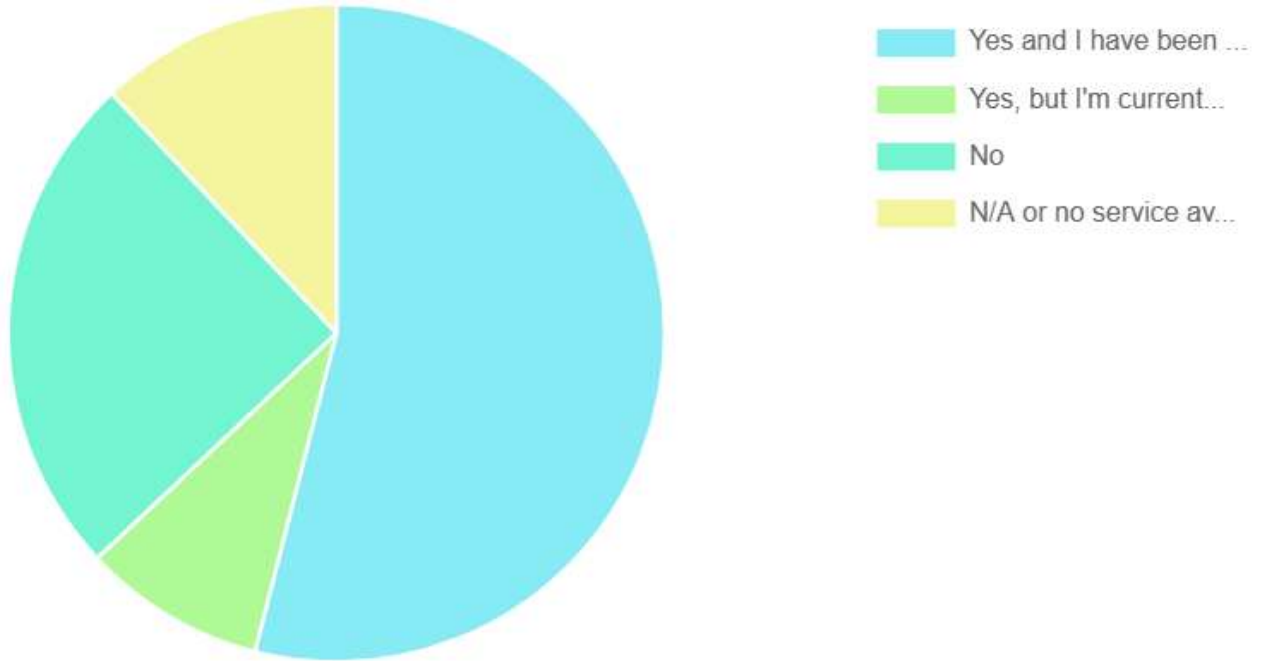
ANSWERS	RESPONSES	
Yes and I have been seen by the ME/CFS specialist service	0%	2
No	36%	218
Yes	46%	281
N/A or no service available	18%	111

612 Answered

234 Skipped

Question 14 ☰ MULTIPLE CHOICE

(After NICE guideline update) Were you referred by your GP to a specialist ME/CFS referral service after three months from the onset of symptoms in order to confirm the diagnosis and prepare a care and management plan?



ANSWERS	RESPONSES	
Yes and I have been seen by the ME/CFS specialist service	54%	127
N/A or no service available in my area	12%	29
No	25%	58
Yes, but I'm currently on a waiting list	9%	20

234 Answered

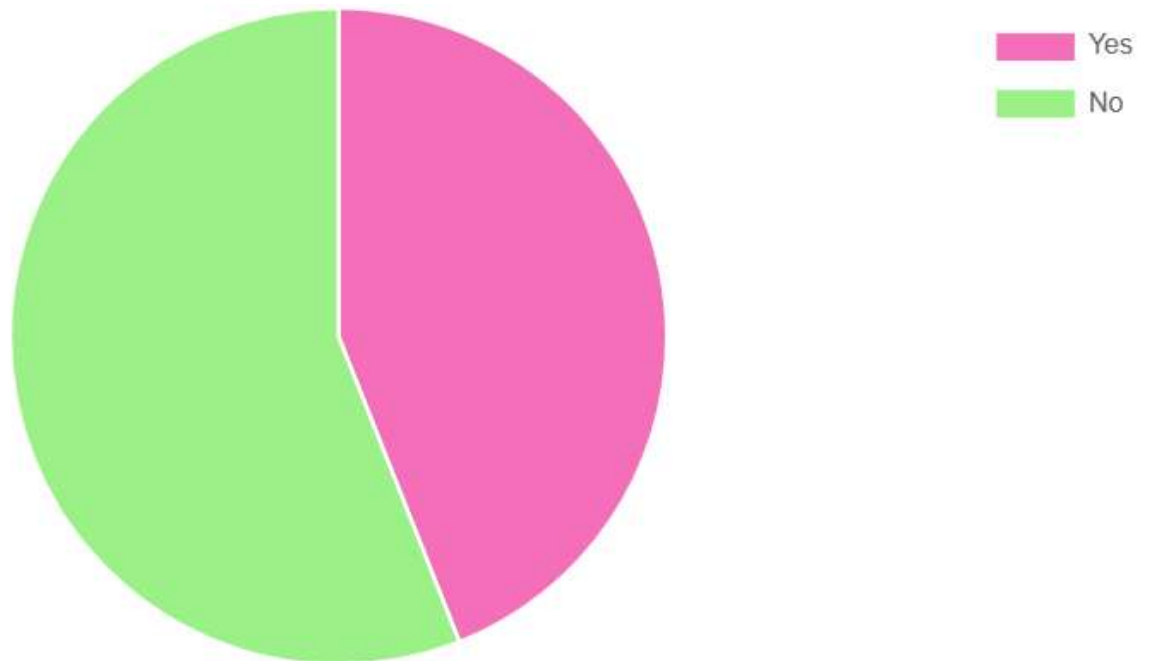
612 Skipped

ANSWERS

DATE

Question 16 ☰ MULTIPLE CHOICE

(Before NICE guideline update) Did your doctor offer medication for symptom management (i.e pain, sleep disturbance)?



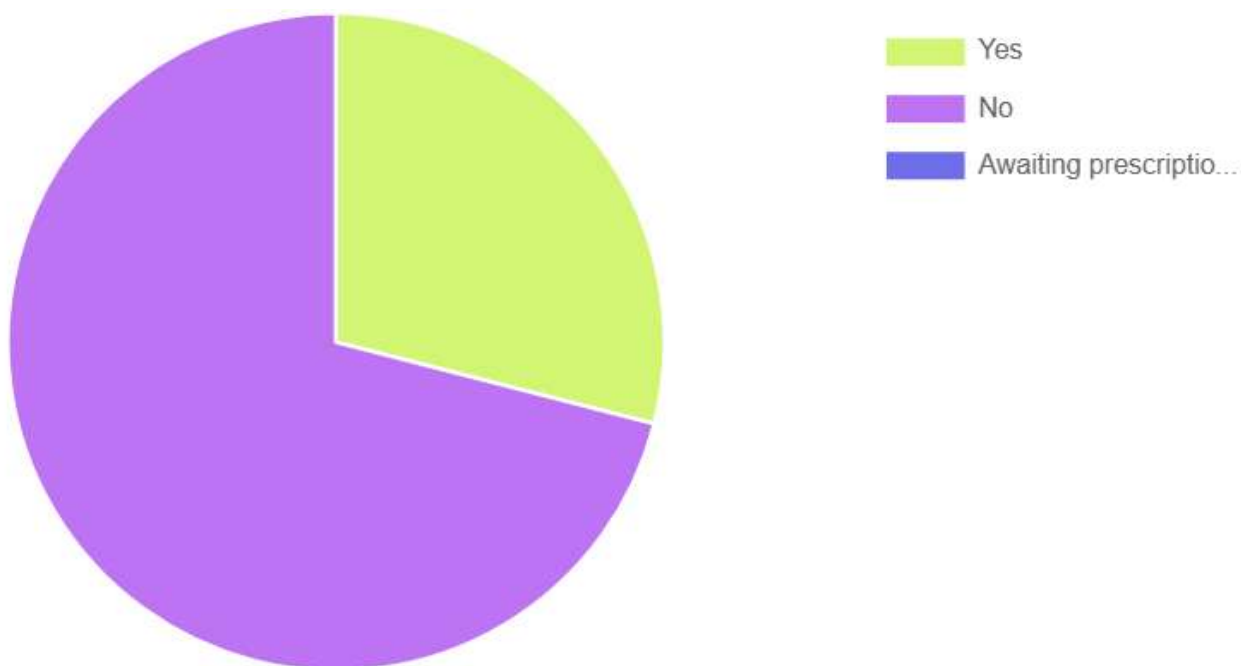
ANSWERS	RESPONSES	
Yes	44%	269
No	56%	343

612 Answered

234 Skipped

Question 17 ☰ MULTIPLE CHOICE

(After NICE guideline update) Did your doctor offer medication for symptom management (i.e pain, sleep disturbance)?



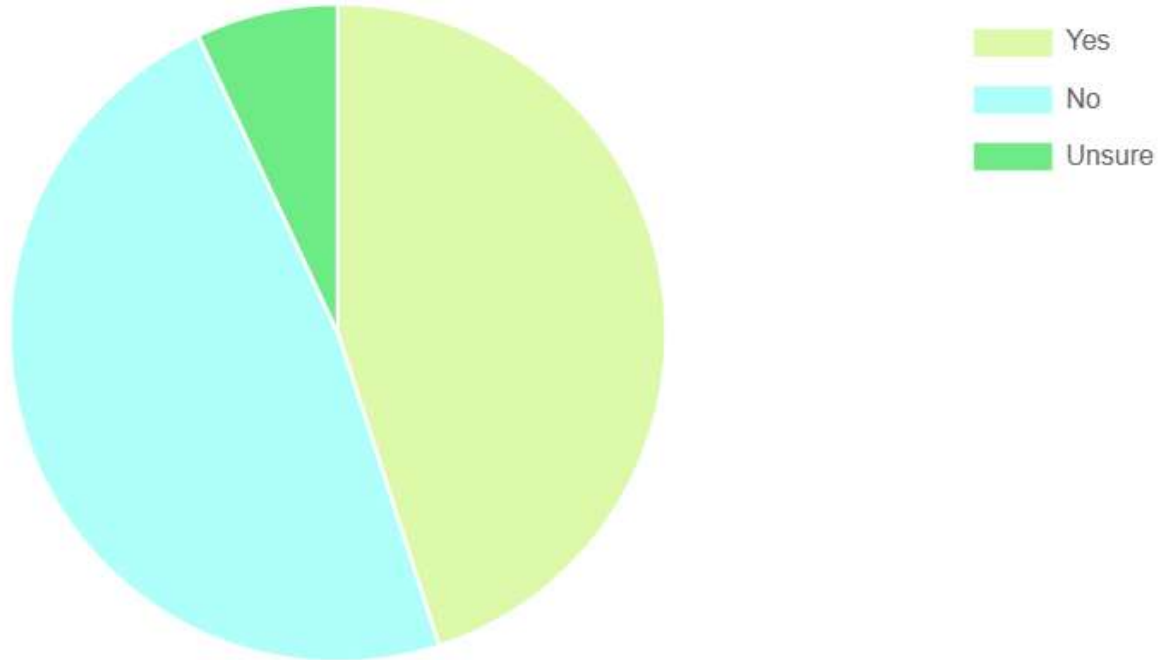
ANSWERS	RESPONSES	
No	71%	165
Yes	29%	68
Awaiting prescription	0%	1

234 Answered

612 Skipped

Question 18 ☰ MULTIPLE CHOICE

(Before NICE guideline update) Were you advised about pacing, activity and energy management?



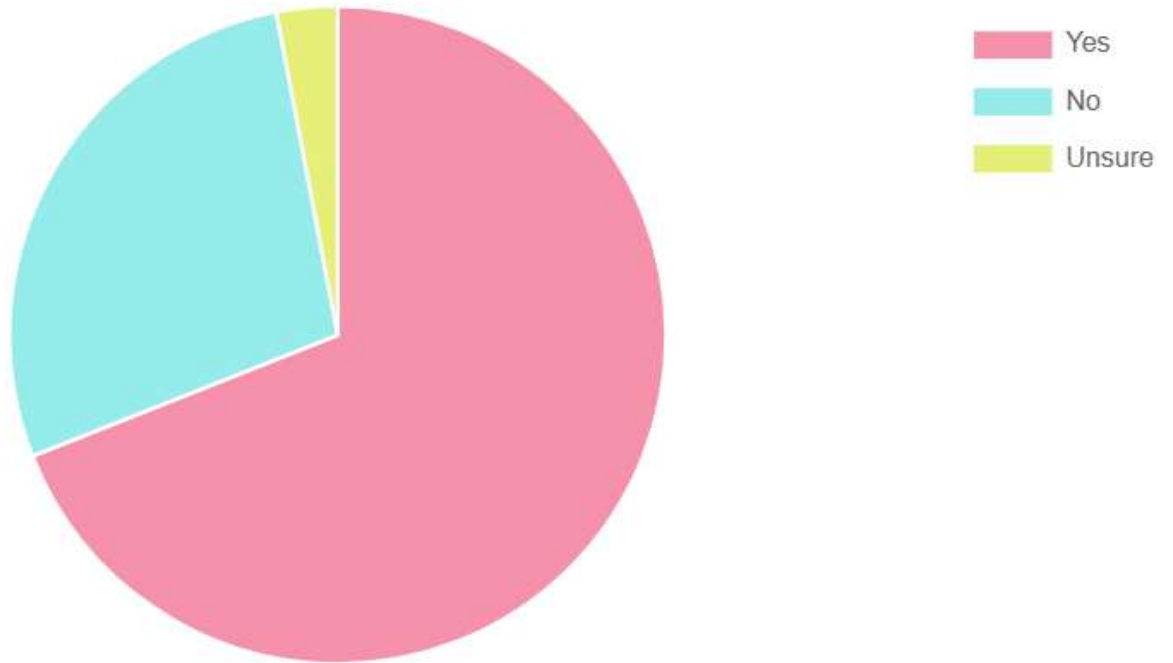
ANSWERS	RESPONSES
Yes	45% 276
No	48% 296
Unsure	7% 40

612 Answered

234 Skipped

Question 19 ☰ MULTIPLE CHOICE

(After NICE guideline update) Were you advised about pacing, activity and energy management?



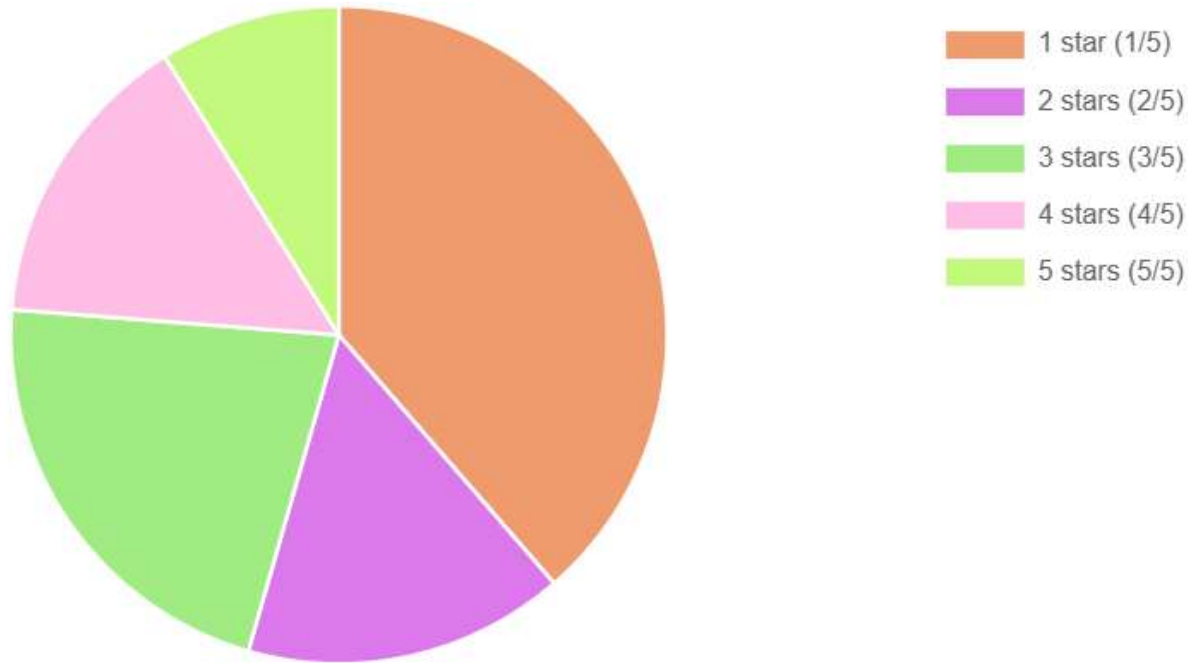
ANSWERS	RESPONSES	
Yes	69%	162
No	28%	65
Unsure	3%	7

234 Answered

612 Skipped

Question 20 ★ RATING

(Before NICE guideline update) Overall were you happy with the diagnosis process? (1-5 i.e. 1=Poor 5=Excellent)



ANSWERS	RESPONSES	
1 star (1/5)	39%	237
2 stars (2/5)	16%	96
3 stars (3/5)	22%	136
4 stars (4/5)	15%	89
5 stars (5/5)	9%	54

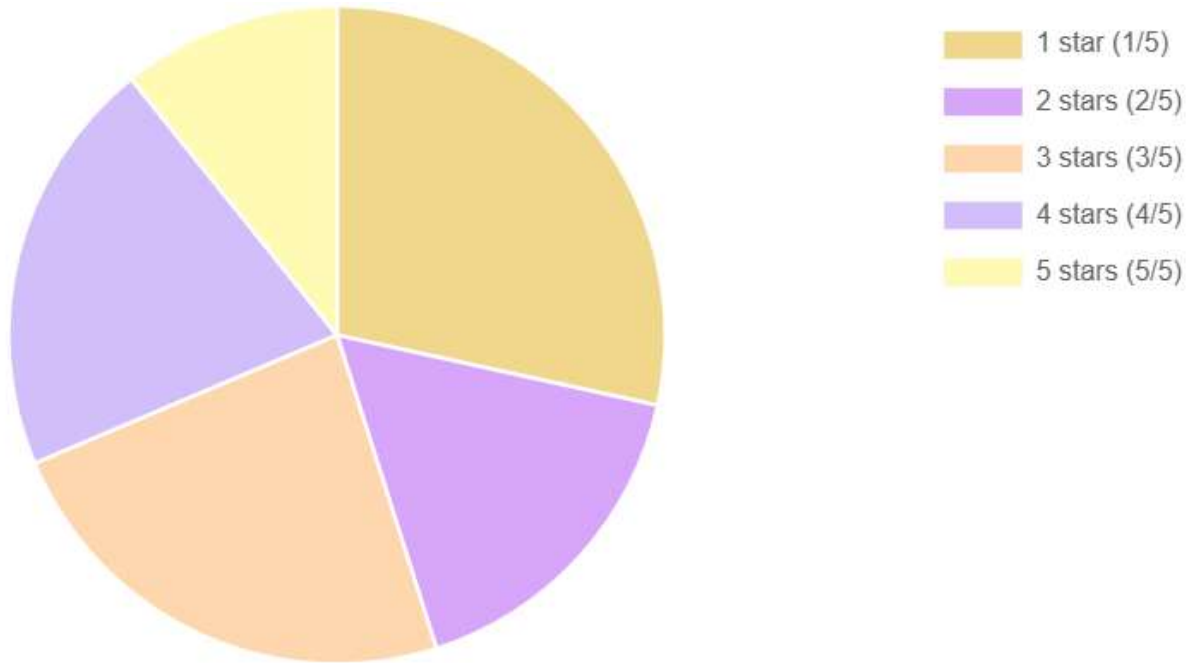
612 Answered

234 Skipped

2.4 Average

Question 21 ★ RATING

(After NICE guideline update) Overall were you happy with the diagnosis process? (1-5 i.e. 1=Poor 5=Excellent)



ANSWERS	RESPONSES	
1 star (1/5)	29%	67
2 stars (2/5)	17%	39
3 stars (3/5)	24%	55
4 stars (4/5)	21%	48
5 stars (5/5)	11%	25

234 Answered

612 Skipped

2.7 Average