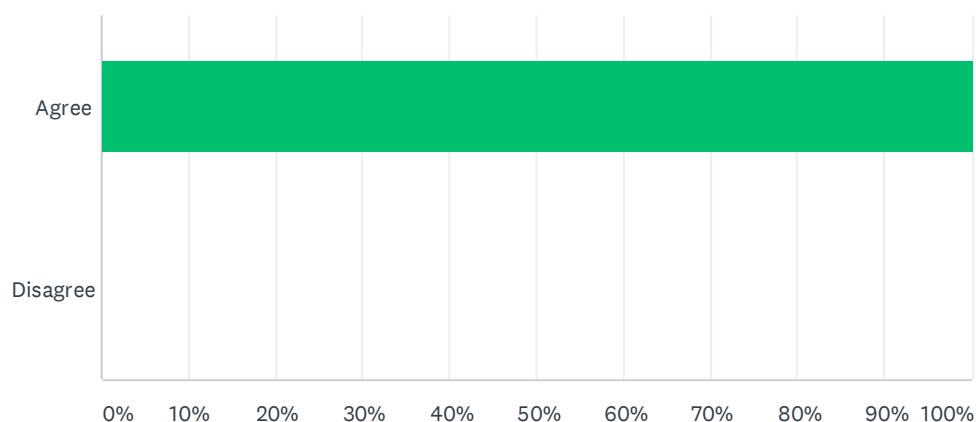


Q1 ELECTRONIC CONSENT Please select your choice below. Clicking on the "agree" button indicates that: • you have read the above information • you voluntarily agree to participate • you are at least 16 years of age If you do not wish to participate in the research study, please decline participation by clicking on the "disagree" button.

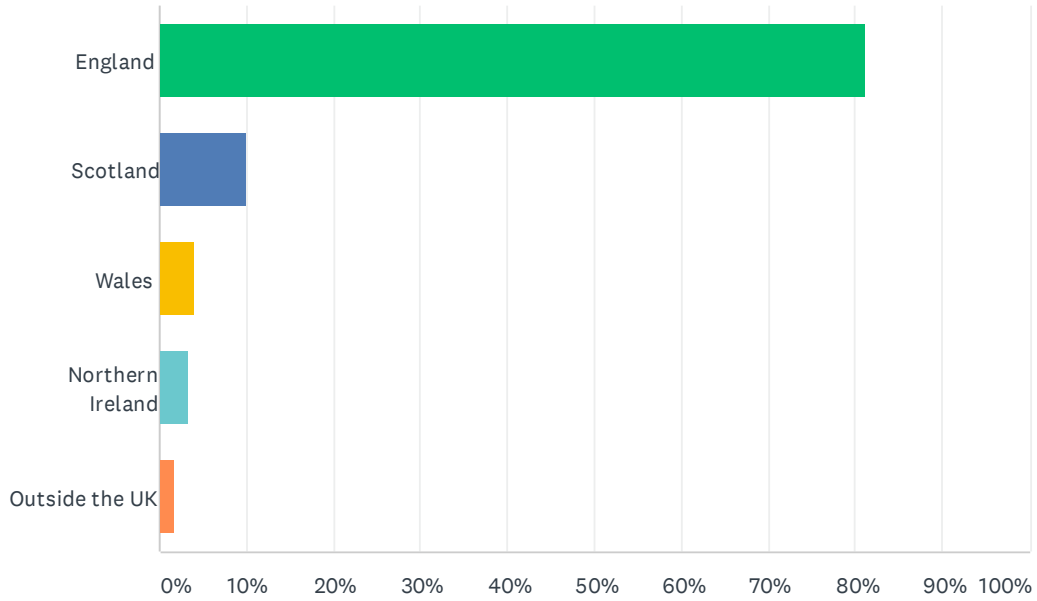
Answered: 180 Skipped: 0



ANSWER CHOICES	RESPONSES
Agree	100.00% 180
Disagree	0.00% 0
TOTAL	180

Q2 Where do you normally live?

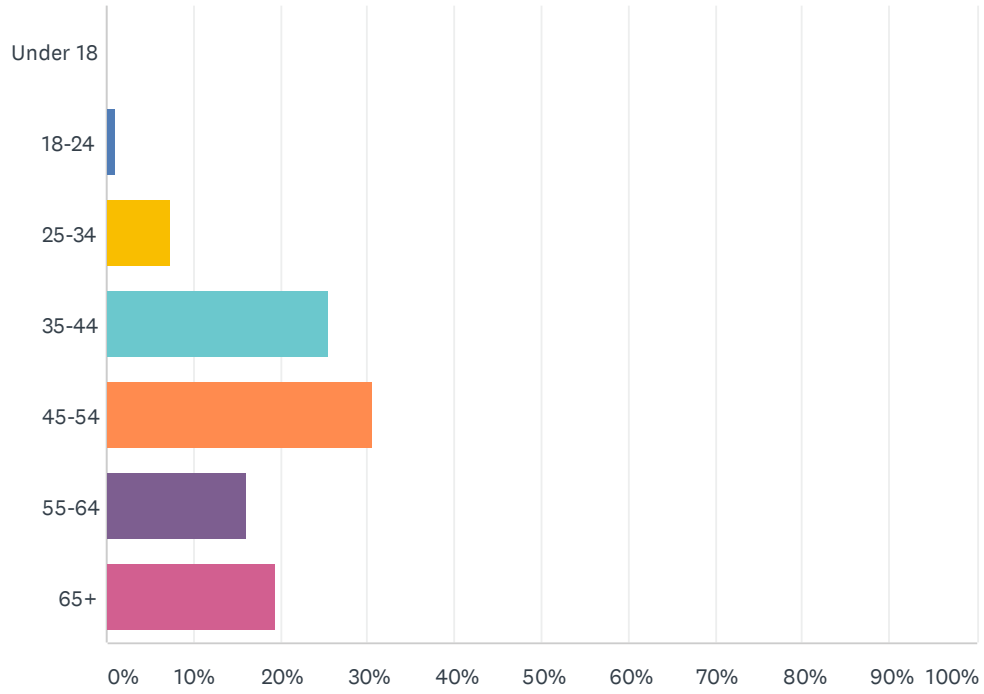
Answered: 180 Skipped: 0



ANSWER CHOICES	RESPONSES	
England	81.11%	146
Scotland	10.00%	18
Wales	3.89%	7
Northern Ireland	3.33%	6
Outside the UK	1.67%	3
TOTAL		180

Q3 What is your age?

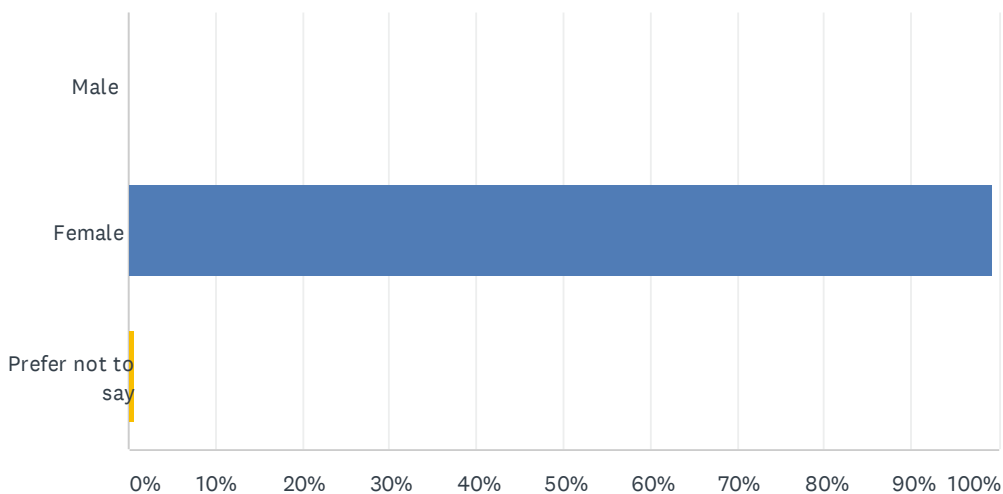
Answered: 180 Skipped: 0



ANSWER CHOICES	RESPONSES	
Under 18	0.00%	0
18-24	1.11%	2
25-34	7.22%	13
35-44	25.56%	46
45-54	30.56%	55
55-64	16.11%	29
65+	19.44%	35
TOTAL		180

Q4 What is your sex? (This question is about the sex you were assigned on your birth certificate, or is on your Gender Recognition Certificate. The next question asks about your gender identity.)

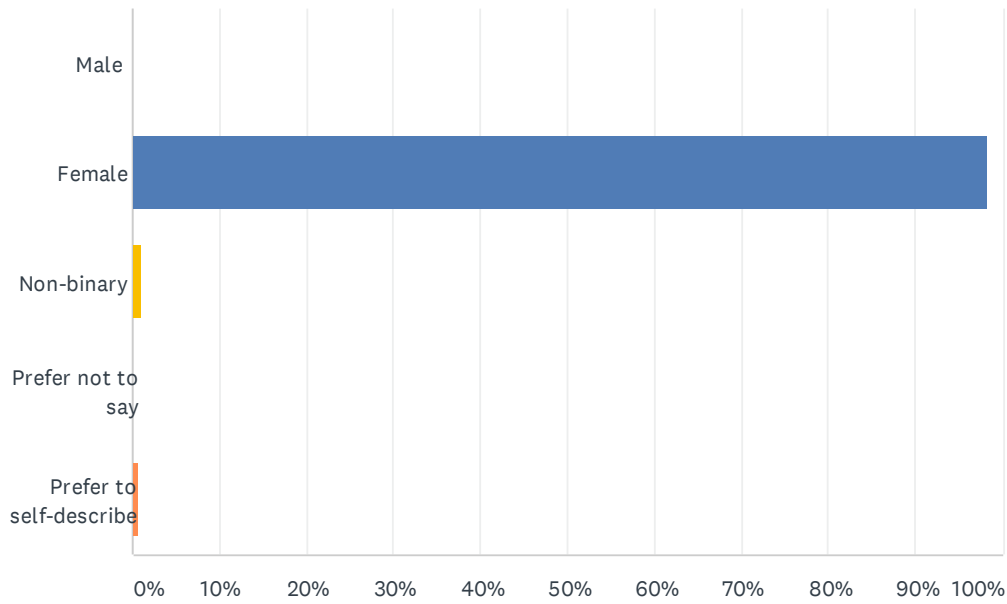
Answered: 180 Skipped: 0



ANSWER CHOICES	RESPONSES
Male	0.00% 0
Female	99.44% 179
Prefer not to say	0.56% 1
TOTAL	180

Q5 What is your gender? (This question is about what gender you identify with.)

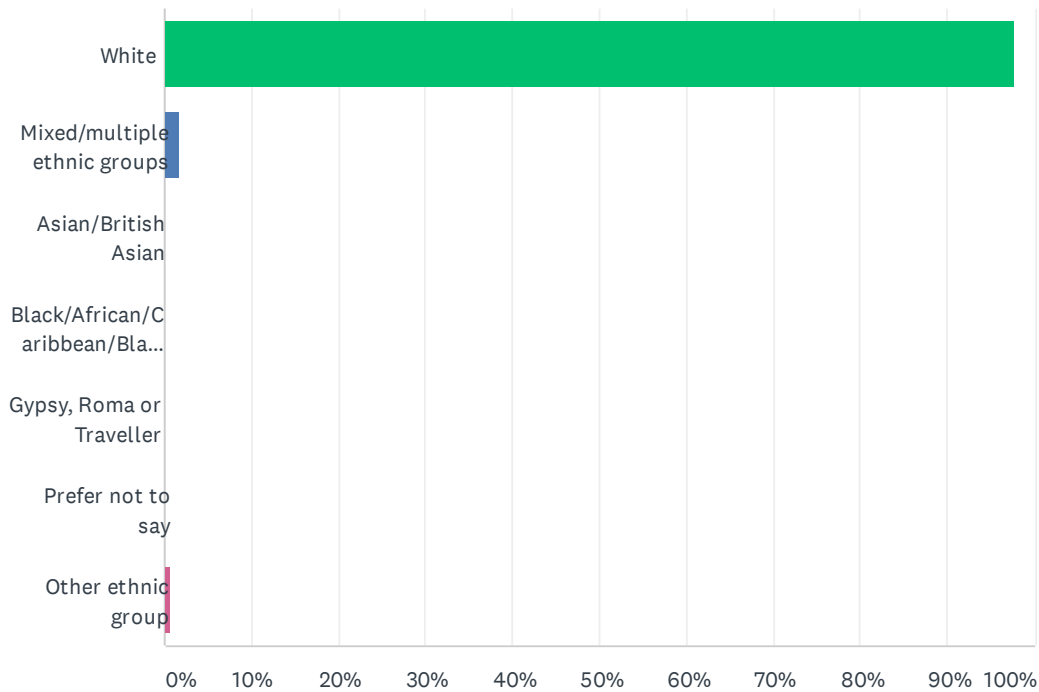
Answered: 180 Skipped: 0



ANSWER CHOICES	RESPONSES
Male	0.00% 0
Female	98.33% 177
Non-binary	1.11% 2
Prefer not to say	0.00% 0
Prefer to self-describe	0.56% 1
TOTAL	180

Q6 What is your ethnicity? Choose one option that best describes your ethnic group or background

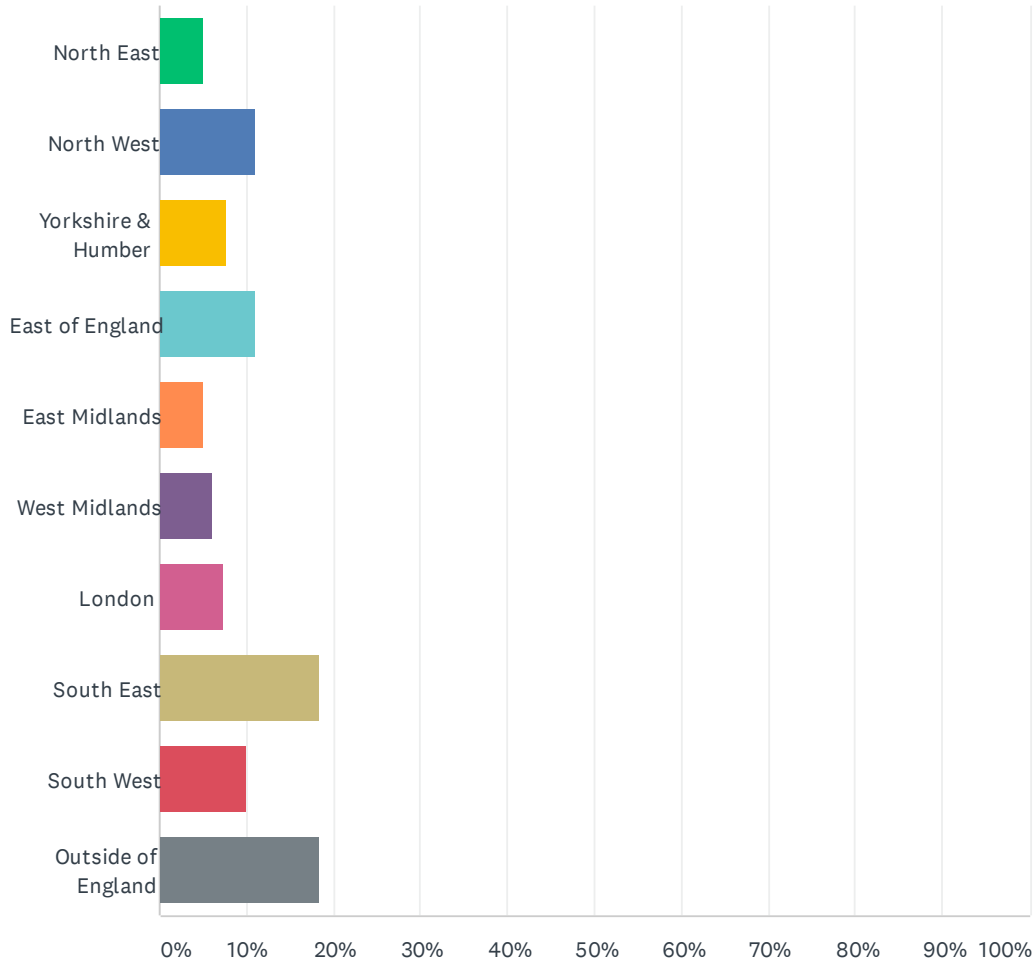
Answered: 180 Skipped: 0



ANSWER CHOICES	RESPONSES
White	97.78% 176
Mixed/multiple ethnic groups	1.67% 3
Asian/British Asian	0.00% 0
Black/African/Caribbean/Black British	0.00% 0
Gypsy, Roma or Traveller	0.00% 0
Prefer not to say	0.00% 0
Other ethnic group	0.56% 1
TOTAL	180

Q7 Where in England do you live?

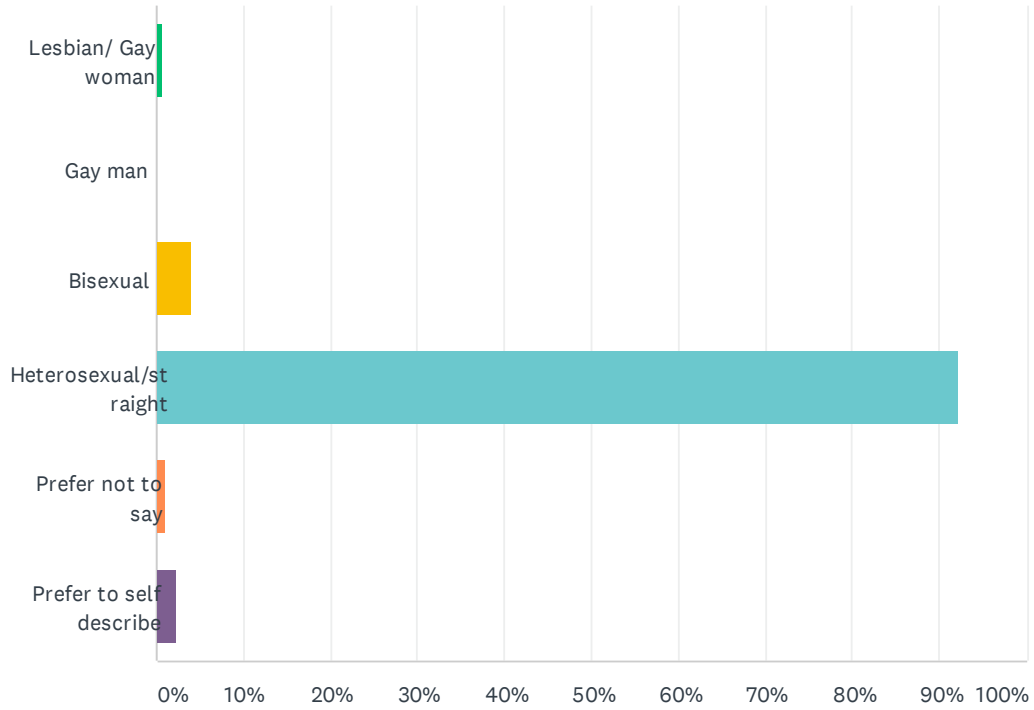
Answered: 180 Skipped: 0



ANSWER CHOICES	RESPONSES
North East	5.00% 9
North West	11.11% 20
Yorkshire & Humber	7.78% 14
East of England	11.11% 20
East Midlands	5.00% 9
West Midlands	6.11% 11
London	7.22% 13
South East	18.33% 33
South West	10.00% 18
Outside of England	18.33% 33
TOTAL	180

Q8 Please select your sexual orientation

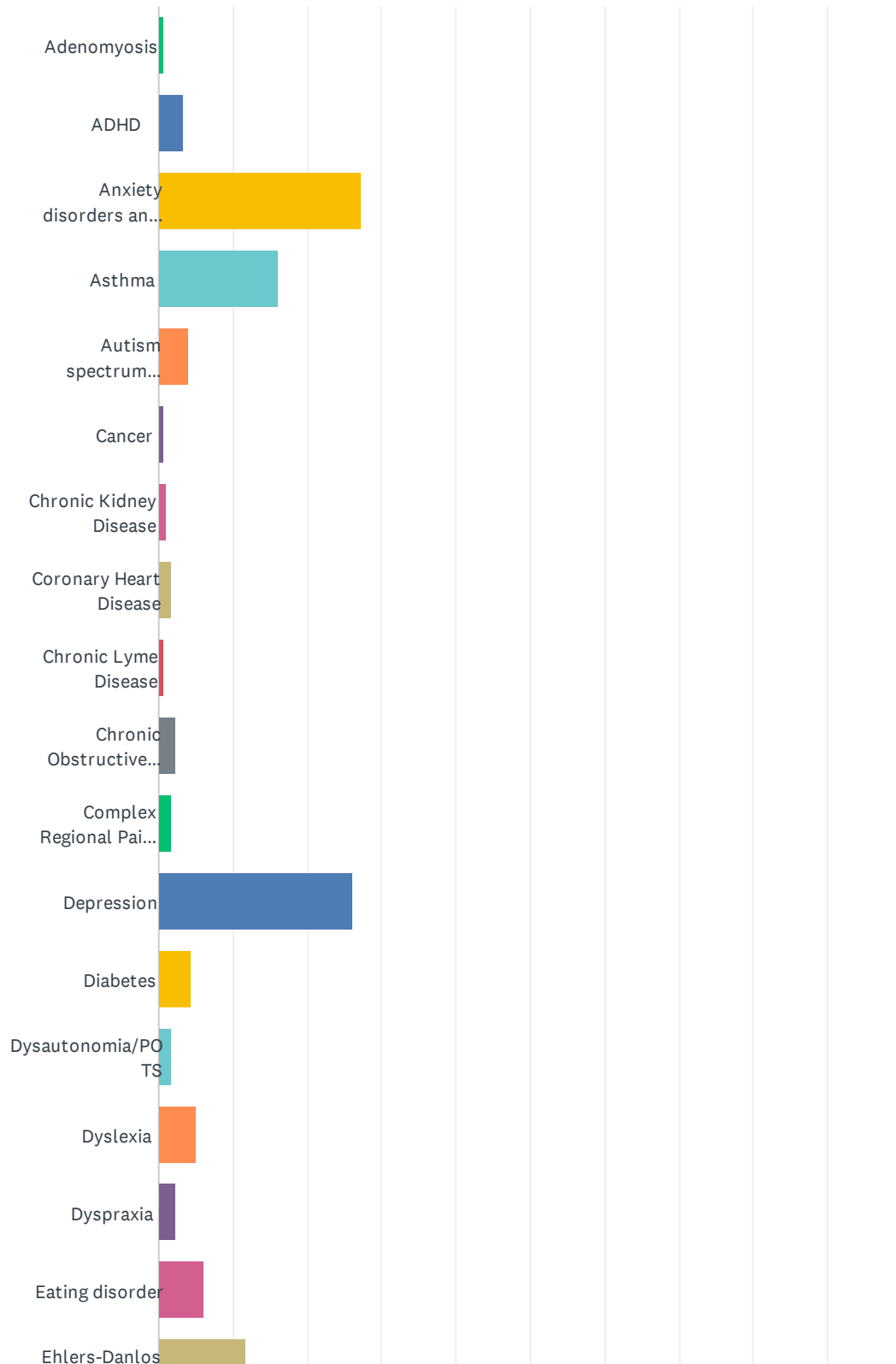
Answered: 180 Skipped: 0

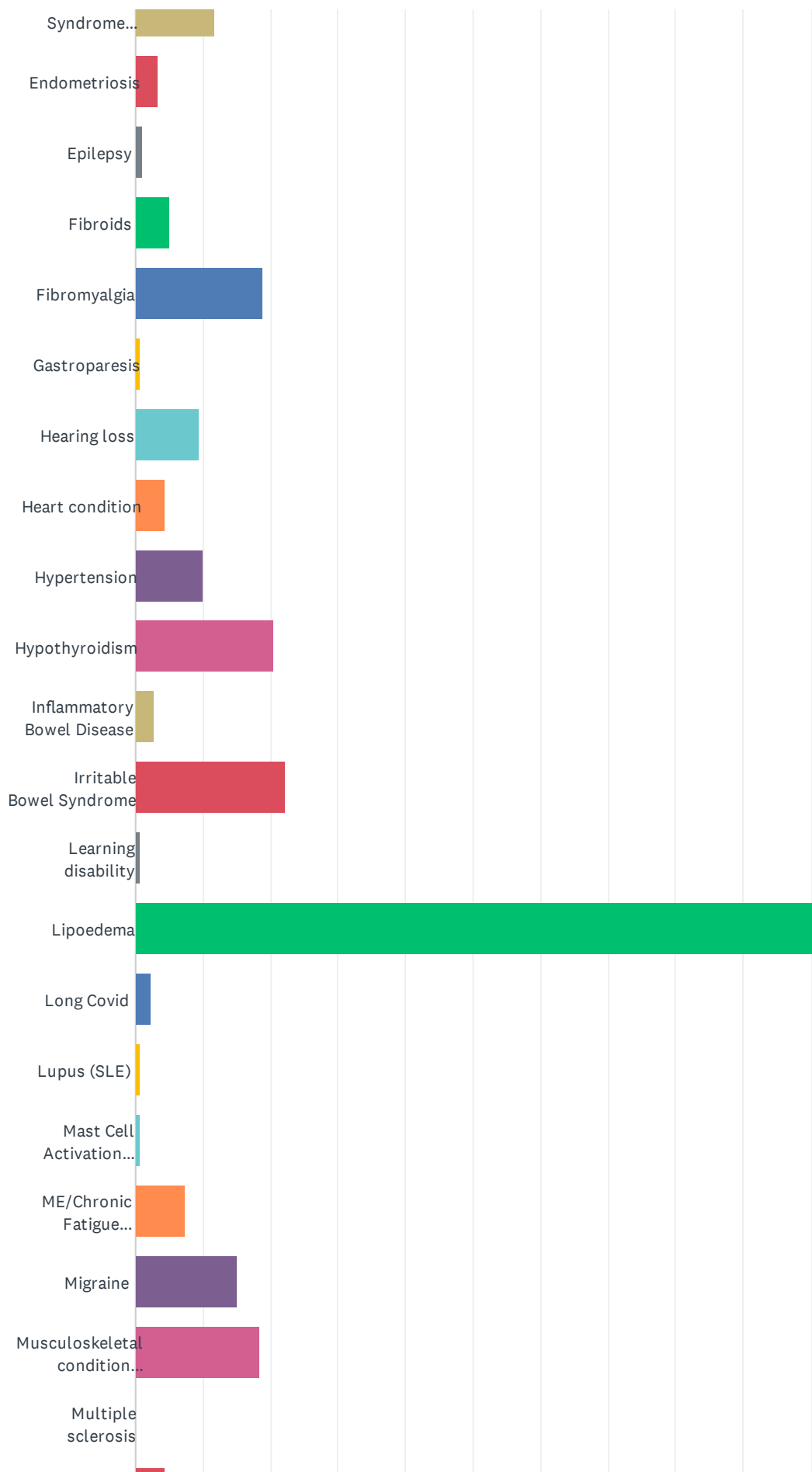


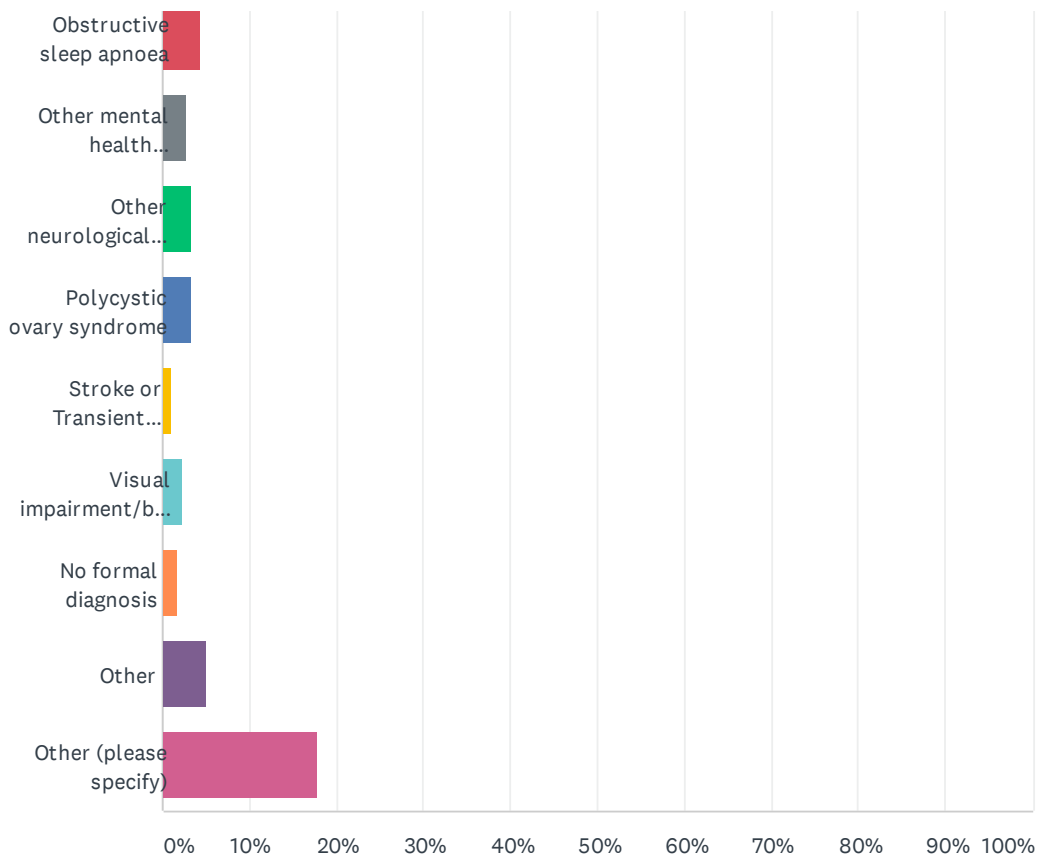
ANSWER CHOICES	RESPONSES	
Lesbian/ Gay woman	0.56%	1
Gay man	0.00%	0
Bisexual	3.89%	7
Heterosexual/straight	92.22%	166
Prefer not to say	1.11%	2
Prefer to self describe	2.22%	4
TOTAL		180

Q9 Please tell us about any health conditions you have. Please tick all that apply and list any health conditions not listed here in the box marked 'Other'

Answered: 180 Skipped: 0







ANSWER CHOICES	RESPONSES	
Adenomyosis	0.56%	1
ADHD	3.33%	6
Anxiety disorders and stress	27.22%	49
Asthma	16.11%	29
Autism spectrum condition	3.89%	7
Cancer	0.56%	1
Chronic Kidney Disease	1.11%	2
Coronary Heart Disease	1.67%	3
Chronic Lyme Disease	0.56%	1
Chronic Obstructive Pulmonary Disease	2.22%	4
Complex Regional Pain Syndrome	1.67%	3
Depression	26.11%	47
Diabetes	4.44%	8
Dysautonomia/POTS	1.67%	3
Dyslexia	5.00%	9
Dyspraxia	2.22%	4
Eating disorder	6.11%	11
Ehlers-Danlos Syndrome (hypermobility)	11.67%	21
Endometriosis	3.33%	6
Epilepsy	1.11%	2
Fibroids	5.00%	9
Fibromyalgia	18.89%	34
Gastroparesis	0.56%	1
Hearing loss	9.44%	17
Heart condition	4.44%	8
Hypertension	10.00%	18
Hypothyroidism	20.56%	37
Inflammatory Bowel Disease	2.78%	5
Irritable Bowel Syndrome	22.22%	40
Learning disability	0.56%	1
Lipoedema	100.00%	180
Long Covid	2.22%	4

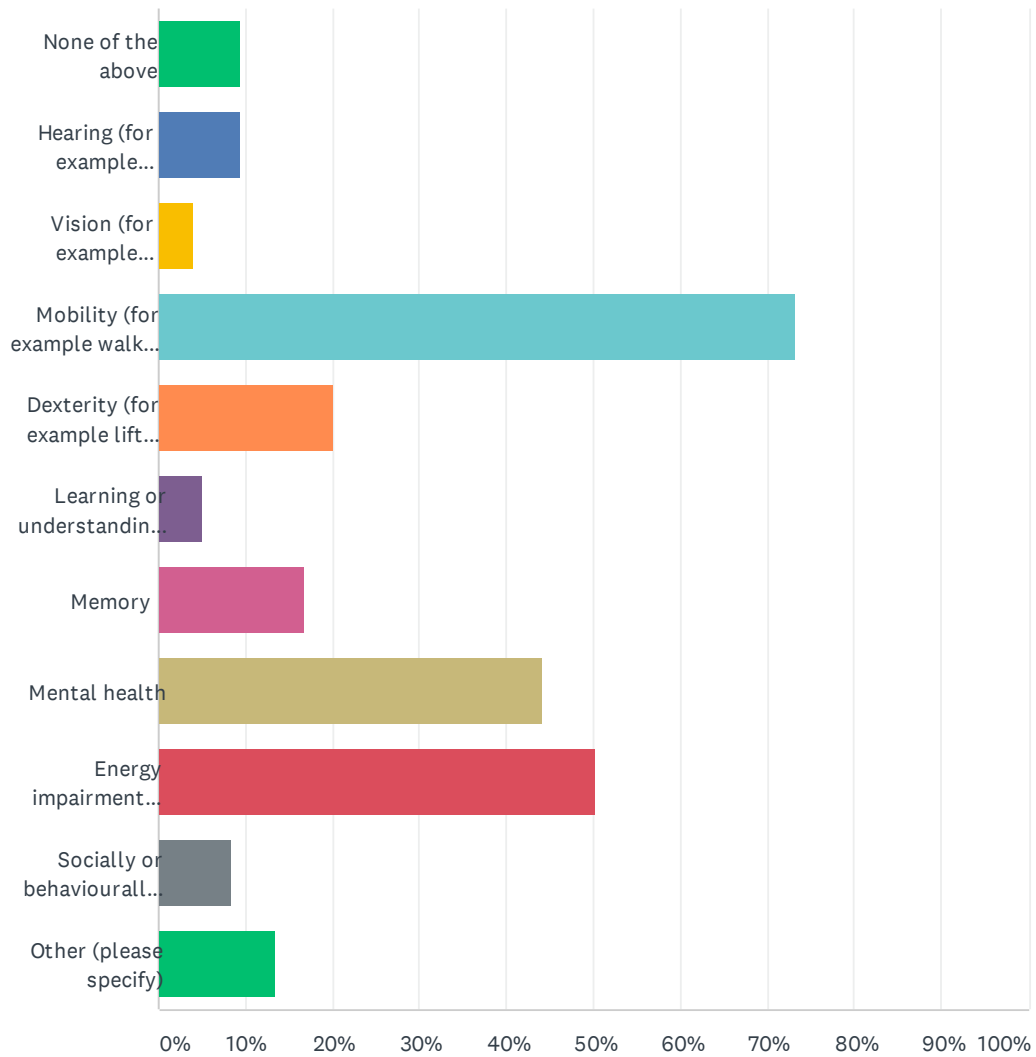
Chronic Illness Inclusion: consultation on chronic illness, disability, women and healthcare

SurveyMonkey

Lupus (SLE)	0.56%	1
Mast Cell Activation Syndrome	0.56%	1
ME/Chronic Fatigue Syndrome	7.22%	13
Migraine	15.00%	27
Musculoskeletal condition (including Arthritis)	18.33%	33
Multiple sclerosis	0.00%	0
Obstructive sleep apnoea	4.44%	8
Other mental health condition	2.78%	5
Other neurological condition	3.33%	6
Polycystic ovary syndrome	3.33%	6
Stroke or Transient Ischaemic Attacks	1.11%	2
Visual impairment/blind	2.22%	4
No formal diagnosis	1.67%	3
Other	5.00%	9
Other (please specify)	17.78%	32
Total Respondents: 180		

Q10 Please tell us about your type of impairment or disability. This is about how your health condition affects you. Please select all that apply.

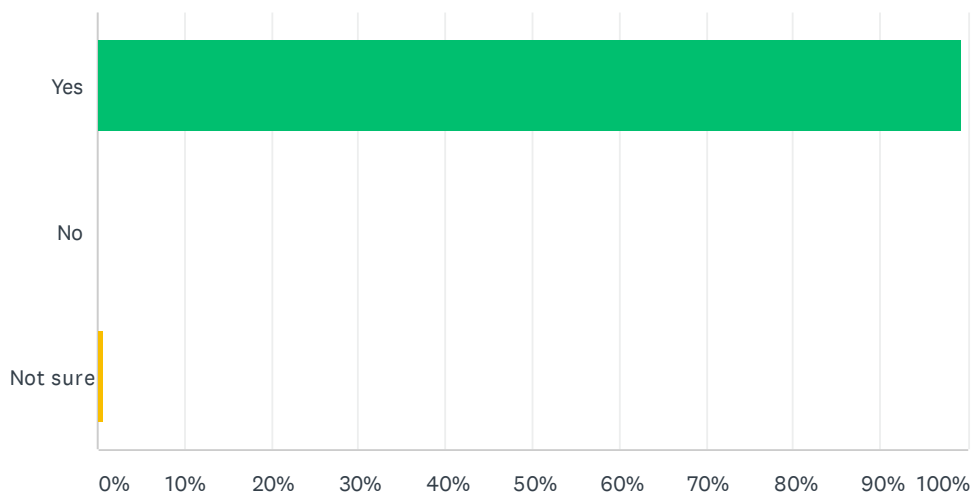
Answered: 179 Skipped: 1



ANSWER CHOICES	RESPONSES	
None of the above	9.50%	17
Hearing (for example deafness or partial hearing)	9.50%	17
Vision (for example blindness or partial sight)	3.91%	7
Mobility (for example walking short distances or climbing stairs)	73.18%	131
Dexterity (for example lifting and carrying objects, using a keyboard)	20.11%	36
Learning or understanding or concentrating	5.03%	9
Memory	16.76%	30
Mental health	44.13%	79
Energy impairment (problems with fatigue or stamina)	50.28%	90
Socially or behaviourally (for example associated with autism spectrum disorder (ASD) which includes Asperger's, or attention deficit hyperactivity disorder (ADHD))	8.38%	15
Other (please specify)	13.41%	24
Total Respondents: 179		

Q11 Have you had your health condition(s) or impairment(s) for 12 months or more, or do you have a condition that is expected to last for 12 months or more?

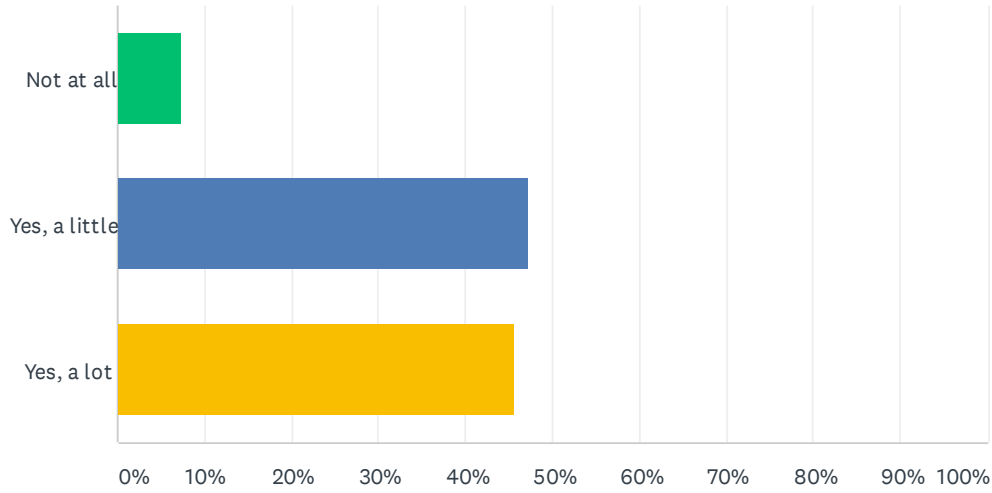
Answered: 180 Skipped: 0



ANSWER CHOICES	RESPONSES
Yes	99.44% 179
No	0.00% 0
Not sure	0.56% 1
TOTAL	180

Q12 Do your condition(s) or illness(es) reduce your ability to carry out day-to-day activities?

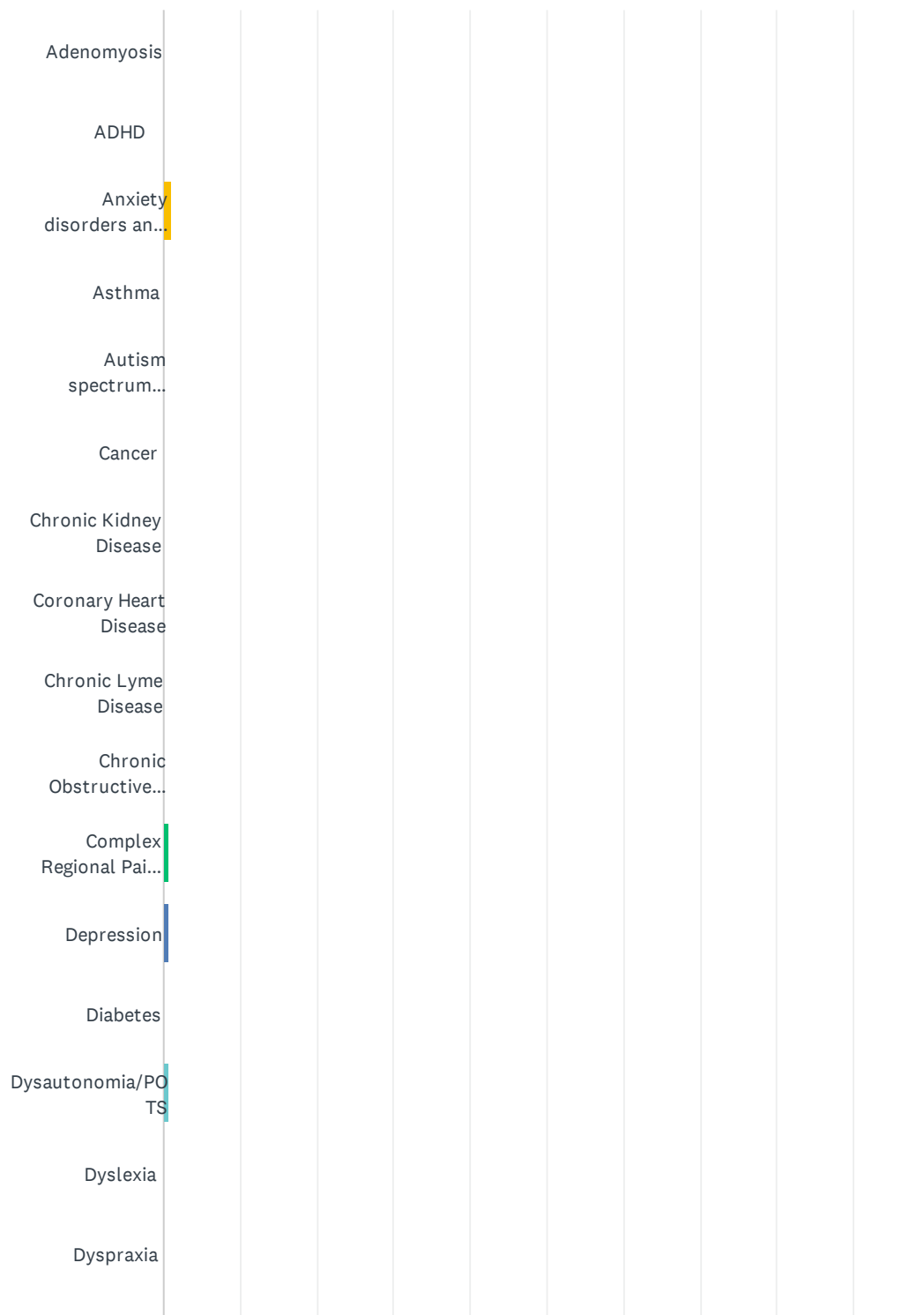
Answered: 180 Skipped: 0

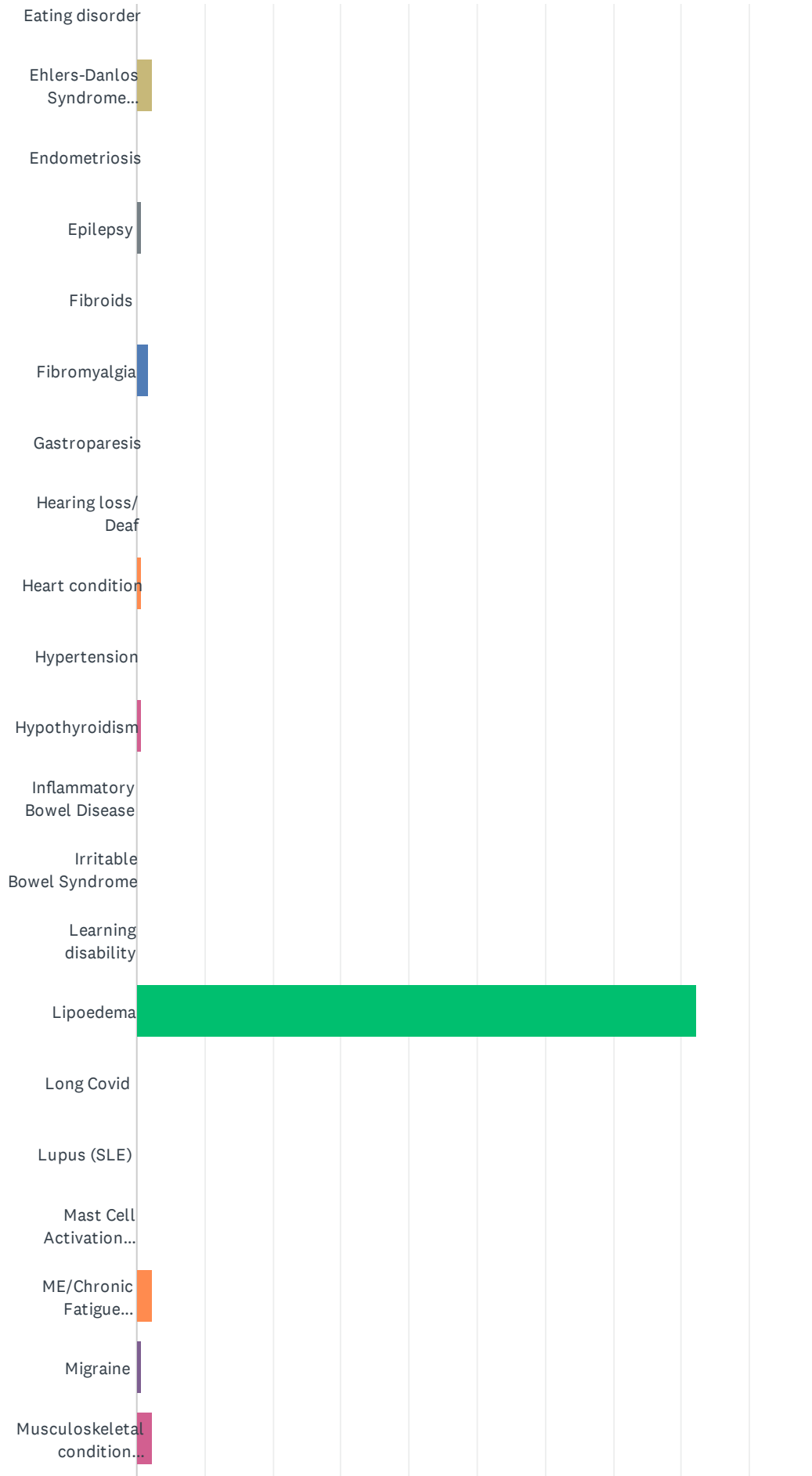


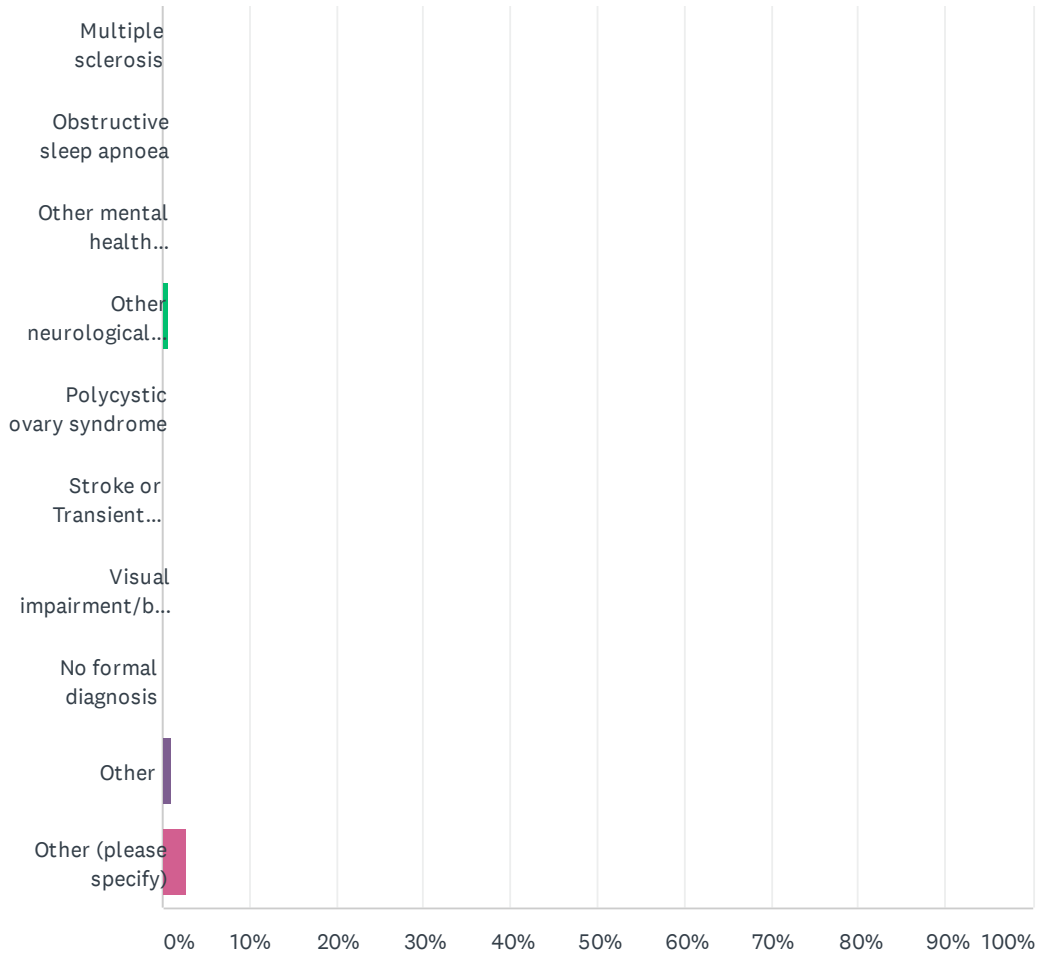
ANSWER CHOICES	RESPONSES
Not at all	7.22% 13
Yes, a little	47.22% 85
Yes, a lot	45.56% 82
TOTAL	180

Q13 Please tell us what you would consider to be your main health condition or impairment. We understand that if you have more than one health condition it can be difficult to say which is the main one. For the purposes of this survey please think about the condition that you feel has the biggest impact on your life, or restricts your activities the most.

Answered: 180 Skipped: 0







ANSWER CHOICES	RESPONSES	
Adenomyosis	0.00%	0
ADHD	0.00%	0
Anxiety disorders and stress	1.11%	2
Asthma	0.00%	0
Autism spectrum condition	0.00%	0
Cancer	0.00%	0
Chronic Kidney Disease	0.00%	0
Coronary Heart Disease	0.00%	0
Chronic Lyme Disease	0.00%	0
Chronic Obstructive Pulmonary Disease	0.00%	0
Complex Regional Pain Syndrome	0.56%	1
Depression	0.56%	1
Diabetes	0.00%	0
Dysautonomia/POTS	0.56%	1
Dyslexia	0.00%	0
Dyspraxia	0.00%	0
Eating disorder	0.00%	0
Ehlers-Danlos Syndrome (hypermobility)	2.22%	4
Endometriosis	0.00%	0
Epilepsy	0.56%	1
Fibroids	0.00%	0
Fibromyalgia	1.67%	3
Gastroparesis	0.00%	0
Hearing loss/ Deaf	0.00%	0
Heart condition	0.56%	1
Hypertension	0.00%	0
Hypothyroidism	0.56%	1
Inflammatory Bowel Disease	0.00%	0
Irritable Bowel Syndrome	0.00%	0
Learning disability	0.00%	0
Lipoedema	82.22%	148
Long Covid	0.00%	0

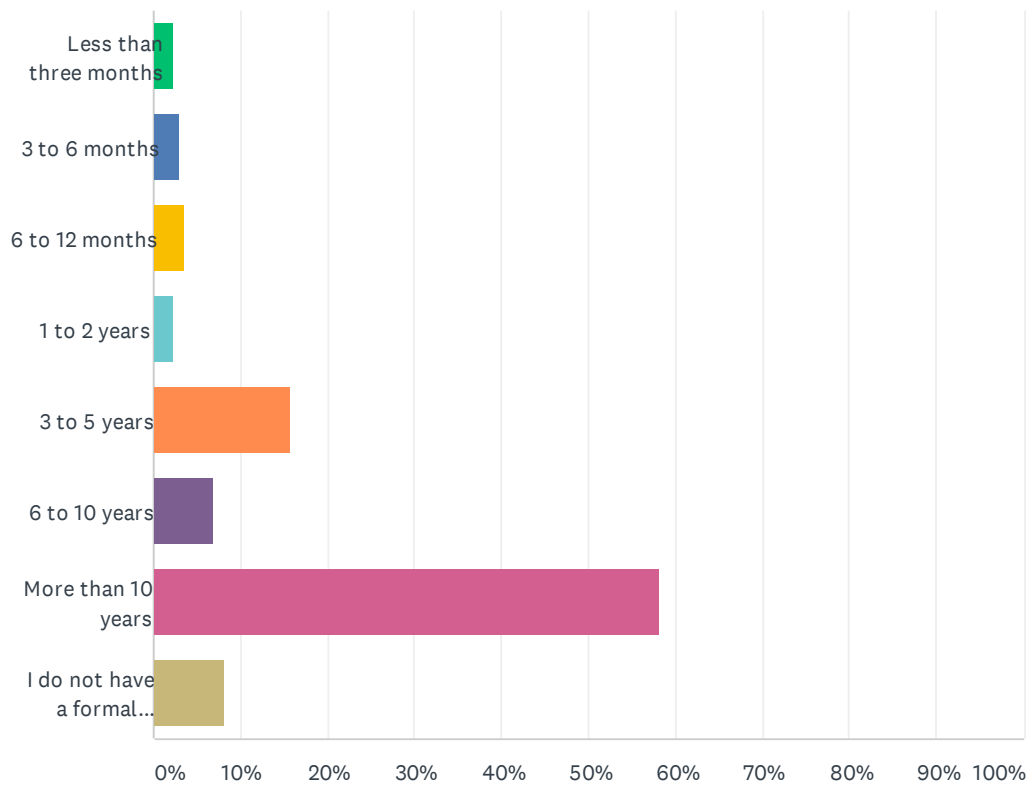
Chronic Illness Inclusion: consultation on chronic illness, disability, women and healthcare

SurveyMonkey

Lupus (SLE)	0.00%	0
Mast Cell Activation Syndrome	0.00%	0
ME/Chronic Fatigue Syndrome	2.22%	4
Migraine	0.56%	1
Musculoskeletal condition (including Arthritis)	2.22%	4
Multiple sclerosis	0.00%	0
Obstructive sleep apnoea	0.00%	0
Other mental health condition	0.00%	0
Other neurological condition	0.56%	1
Polycystic ovary syndrome	0.00%	0
Stroke or Transient Ischaemic Attacks	0.00%	0
Visual impairment/blind	0.00%	0
No formal diagnosis	0.00%	0
Other	1.11%	2
Other (please specify)	2.78%	5
TOTAL		180

Q14 Thinking about your main health condition, how long was it from first experiencing symptoms to receiving your diagnosis?

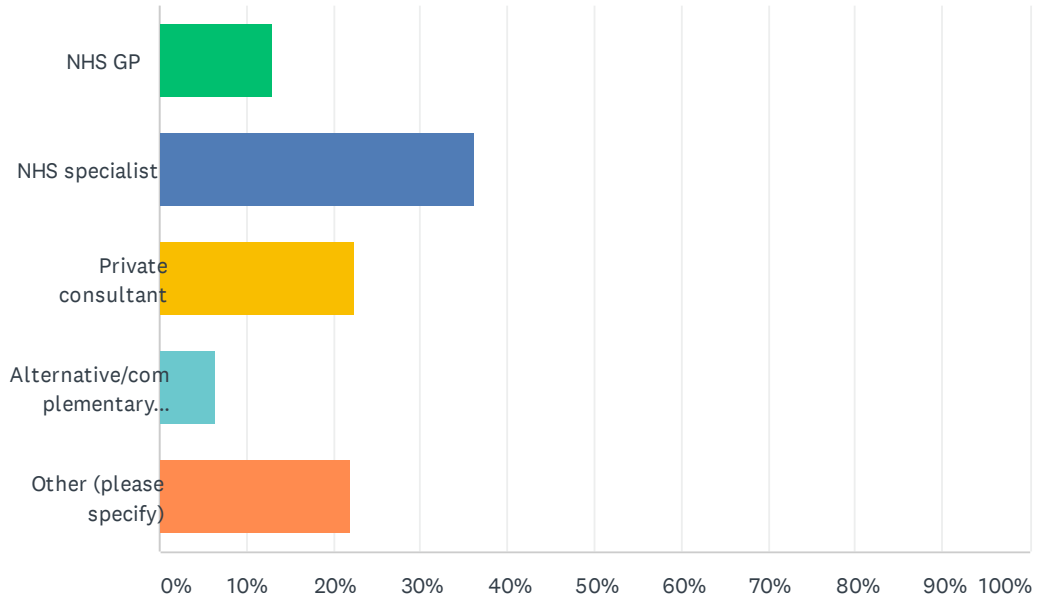
Answered: 172 Skipped: 8



ANSWER CHOICES	RESPONSES	
Less than three months	2.33%	4
3 to 6 months	2.91%	5
6 to 12 months	3.49%	6
1 to 2 years	2.33%	4
3 to 5 years	15.70%	27
6 to 10 years	6.98%	12
More than 10 years	58.14%	100
I do not have a formal diagnosis	8.14%	14
TOTAL		172

Q15 Who diagnosed your condition?

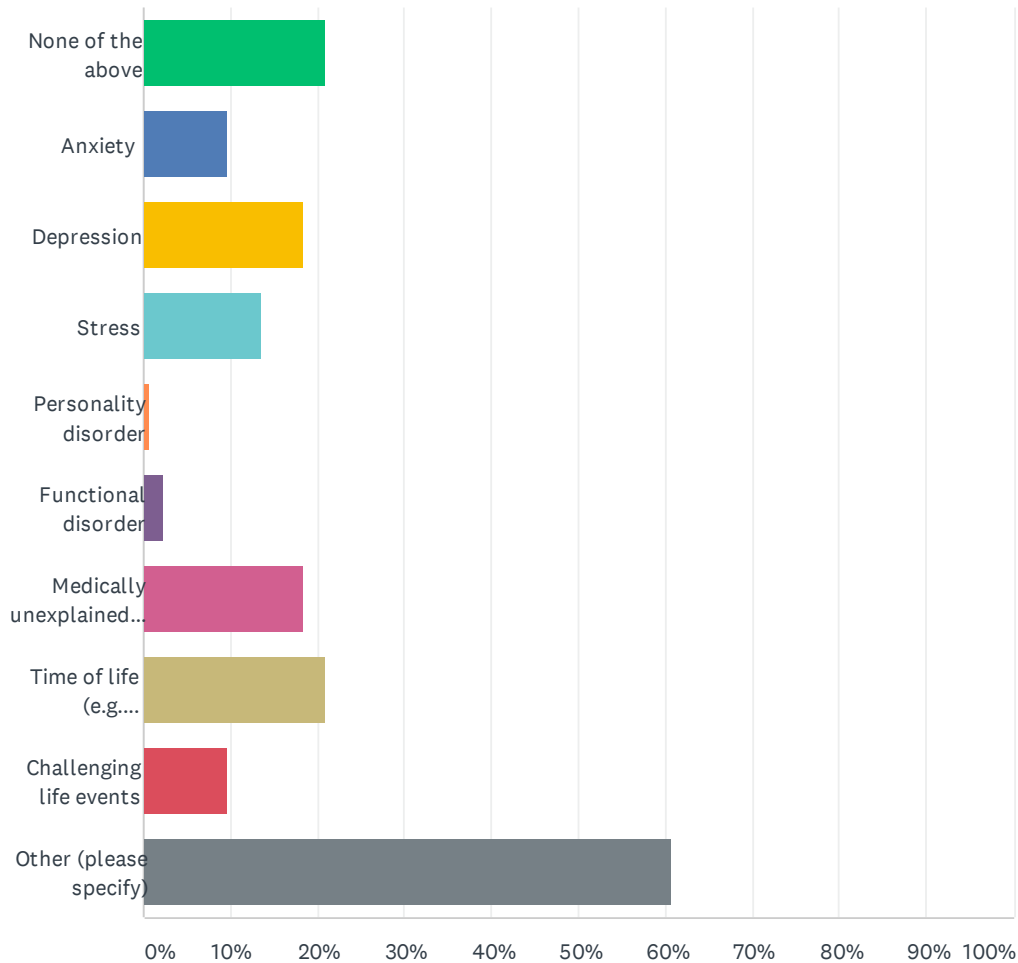
Answered: 169 Skipped: 11



ANSWER CHOICES	RESPONSES
NHS GP	13.02% 22
NHS specialist	36.09% 61
Private consultant	22.49% 38
Alternative/complementary therapist	6.51% 11
Other (please specify)	21.89% 37
TOTAL	169

Q16 Before you obtained your current diagnosis were you given any of the following explanations or diagnoses for your symptoms that have proved to be incorrect? Please tick all that apply

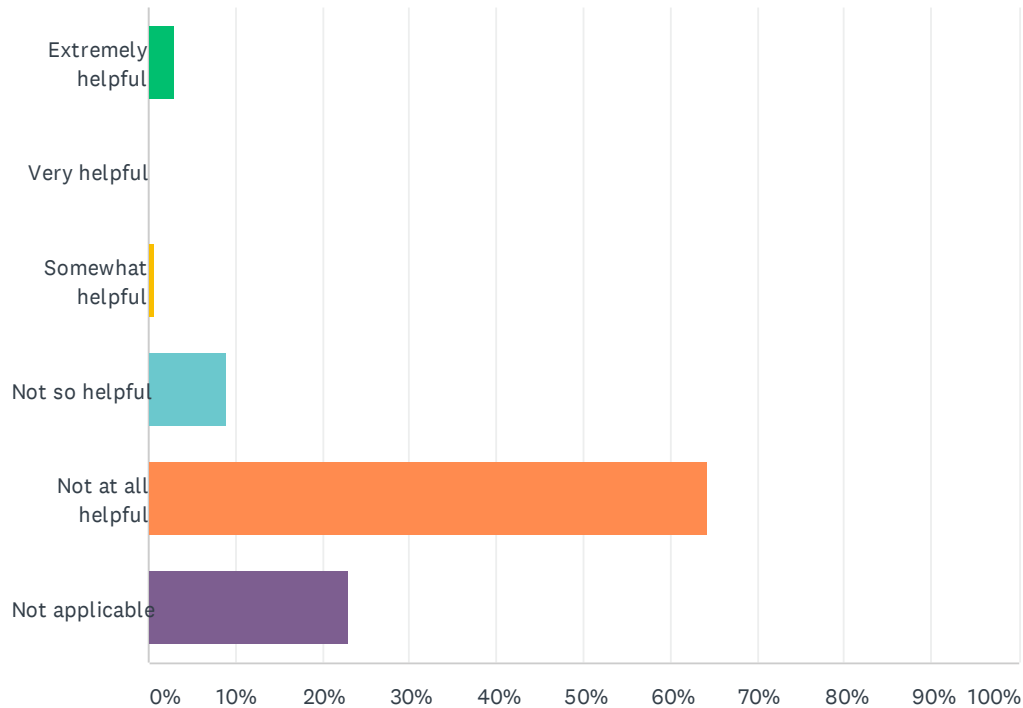
Answered: 168 Skipped: 12



ANSWER CHOICES	RESPONSES	
None of the above	20.83%	35
Anxiety	9.52%	16
Depression	18.45%	31
Stress	13.69%	23
Personality disorder	0.60%	1
Functional disorder	2.38%	4
Medically unexplained symptoms	18.45%	31
Time of life (e.g. menopause)	20.83%	35
Challenging life events	9.52%	16
Other (please specify)	60.71%	102
Total Respondents: 168		

Q17 If you were given any of these explanations or diagnoses before receiving your current diagnosis, how helpful did you find this previous explanation or diagnosis?

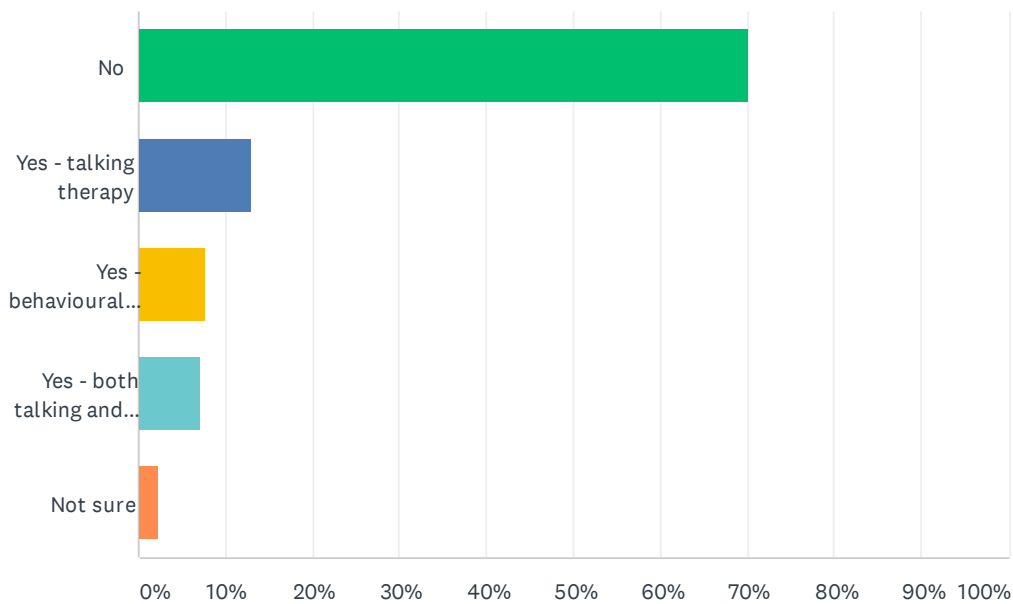
Answered: 165 Skipped: 15



ANSWER CHOICES	RESPONSES
Extremely helpful	3.03% 5
Very helpful	0.00% 0
Somewhat helpful	0.61% 1
Not so helpful	9.09% 15
Not at all helpful	64.24% 106
Not applicable	23.03% 38
TOTAL	165

Q18 Have you ever received either a talking therapy (e.g. cognitive behavioural therapy), or a behavioural therapy (e.g. exercise) for the treatment of physical symptoms such as pain or fatigue? (This question is not asking about talking therapy for mental distress or a diagnosed mental health condition, only for physical symptoms)

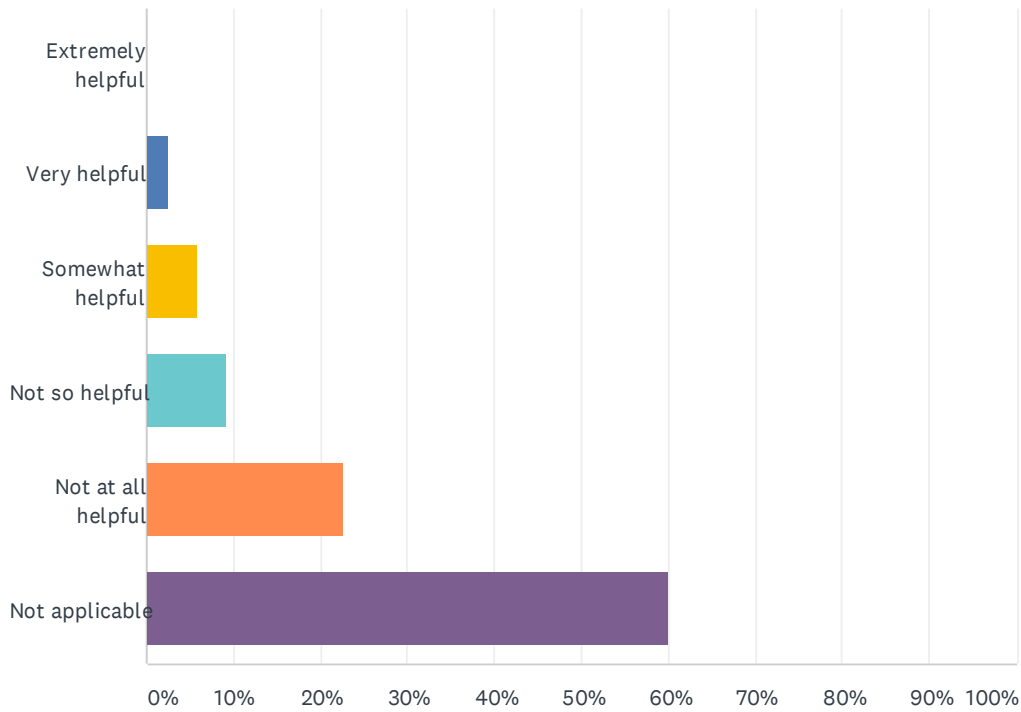
Answered: 170 Skipped: 10



ANSWER CHOICES	RESPONSES	
No	70.00%	119
Yes - talking therapy	12.94%	22
Yes - behavioural therapy	7.65%	13
Yes - both talking and behavioural therapy	7.06%	12
Not sure	2.35%	4
TOTAL		170

Q19 If you answered yes, how helpful did you find the talking therapy in alleviating physical symptoms?

Answered: 120 Skipped: 60



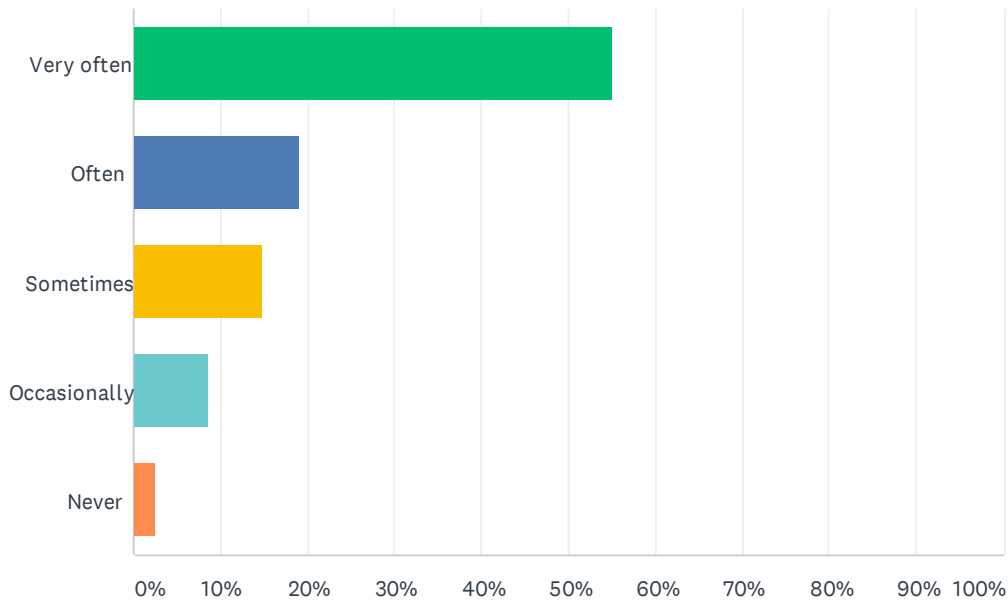
ANSWER CHOICES	RESPONSES	
Extremely helpful	0.00%	0
Very helpful	2.50%	3
Somewhat helpful	5.83%	7
Not so helpful	9.17%	11
Not at all helpful	22.50%	27
Not applicable	60.00%	72
TOTAL		120

Q20 Please use this space to explain your experiences further if you wish

Answered: 57 Skipped: 123

Q21 Have there been any instances where you felt you were not listened to by health or care professionals?

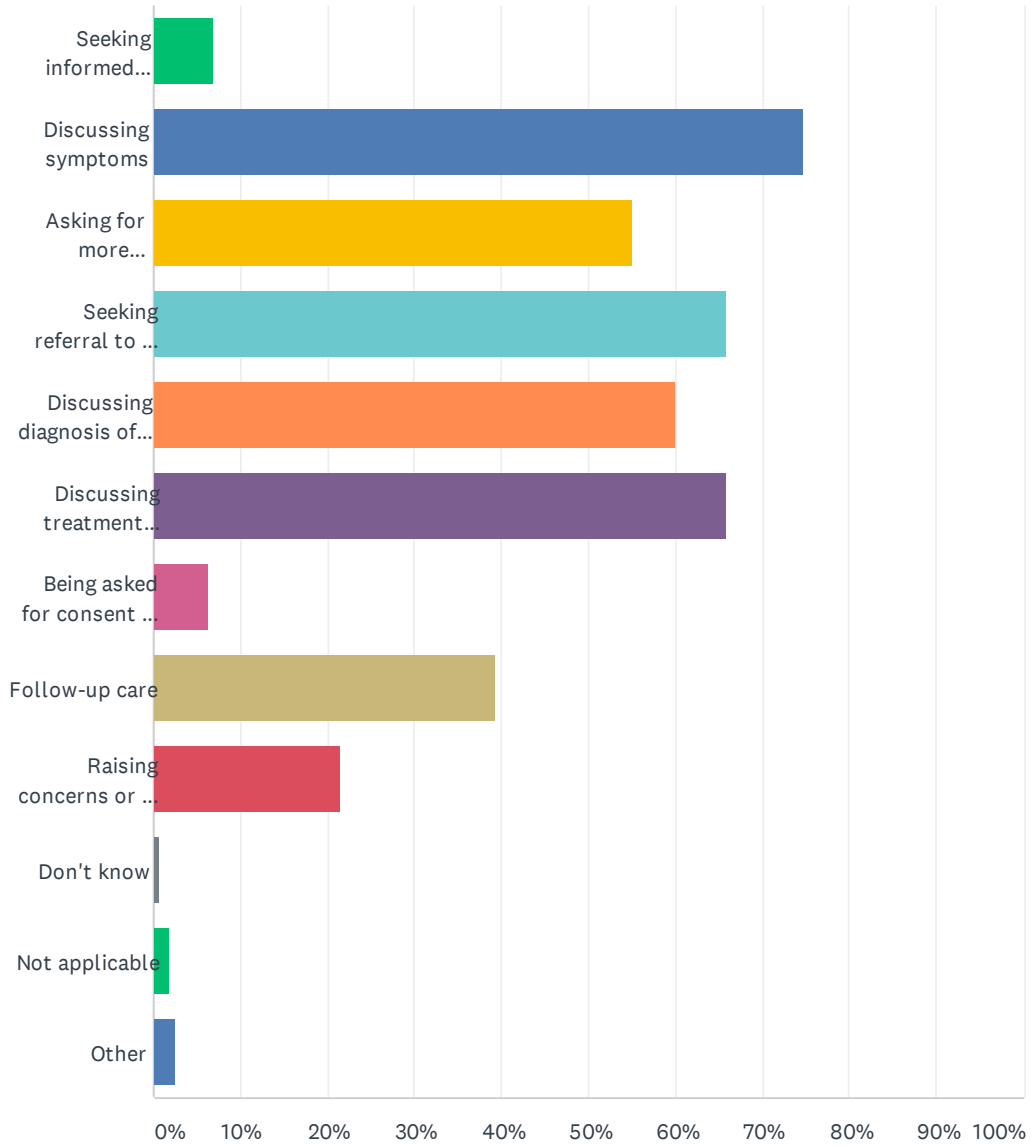
Answered: 162 Skipped: 18



ANSWER CHOICES	RESPONSES	
Very often	54.94%	89
Often	19.14%	31
Sometimes	14.81%	24
Occasionally	8.64%	14
Never	2.47%	4
TOTAL		162

Q22 Please select the nature of the discussion selecting all that apply

Answered: 158 Skipped: 22



ANSWER CHOICES	RESPONSES	
Seeking informed consent	6.96%	11
Discussing symptoms	74.68%	118
Asking for more information about an issue or condition	55.06%	87
Seeking referral to a specialist	65.82%	104
Discussing diagnosis of a condition or disability	60.13%	95
Discussing treatment options	65.82%	104
Being asked for consent to a procedure or course of action	6.33%	10
Follow-up care	39.24%	62
Raising concerns or a complaint	21.52%	34
Don't know	0.63%	1
Not applicable	1.90%	3
Other	2.53%	4
Total Respondents: 158		

Q23 Have there been any instances where you felt you were not listened to in relation to specific health issues or conditions? Enter up to 2 examples

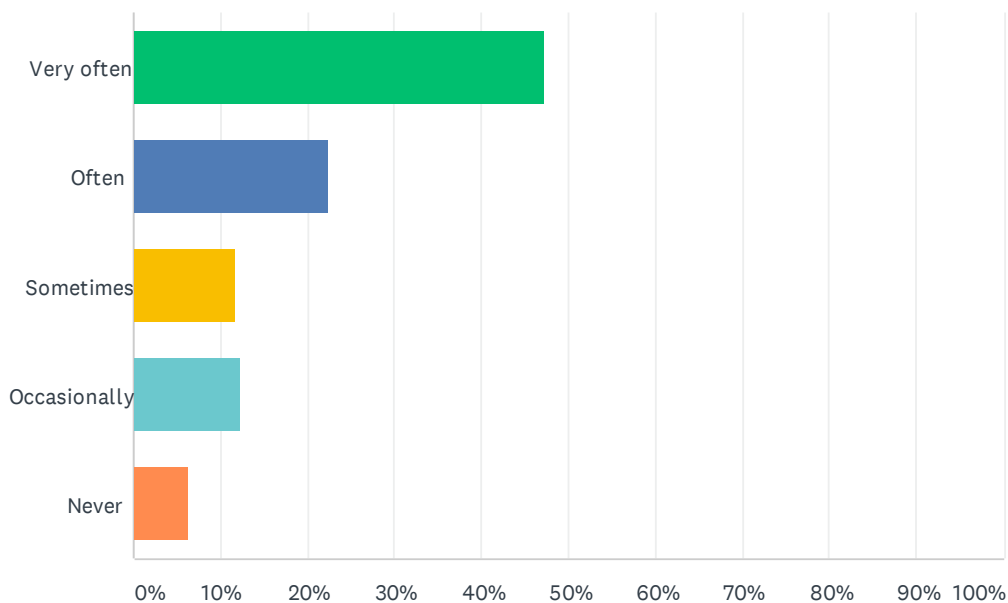
Answered: 120 Skipped: 60

Q24 Example 2

Answered: 86 Skipped: 94

Q25 Have there been instances where you felt your account of how your condition affects you and impacts on your life was not believed by a health or social care professional?

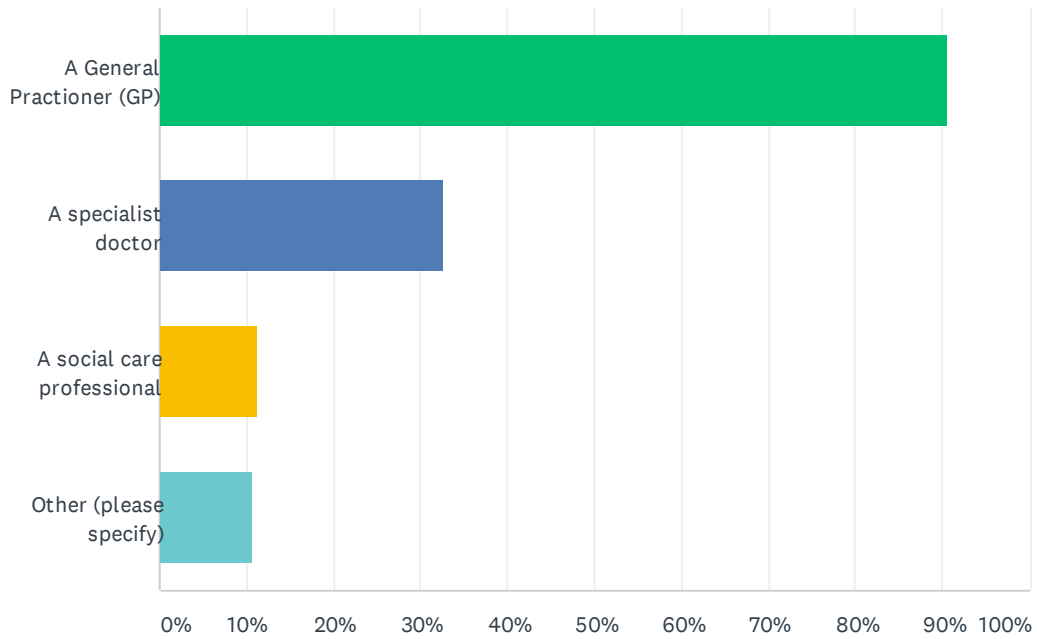
Answered: 161 Skipped: 19



ANSWER CHOICES	RESPONSES	
Very often	47.20%	76
Often	22.36%	36
Sometimes	11.80%	19
Occasionally	12.42%	20
Never	6.21%	10
TOTAL		161

Q26 Was this experience of being disbelieved in relation to

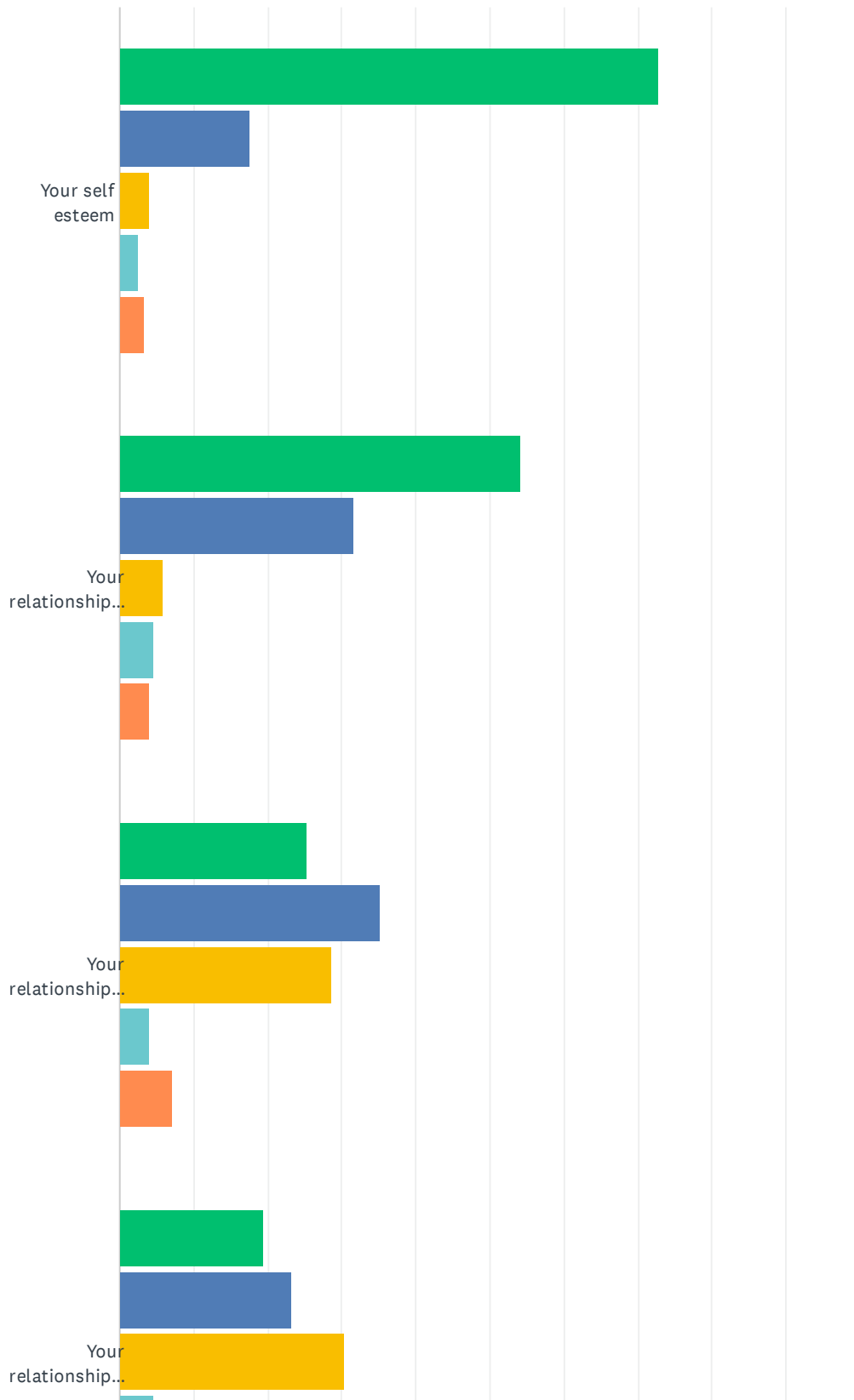
Answered: 150 Skipped: 30

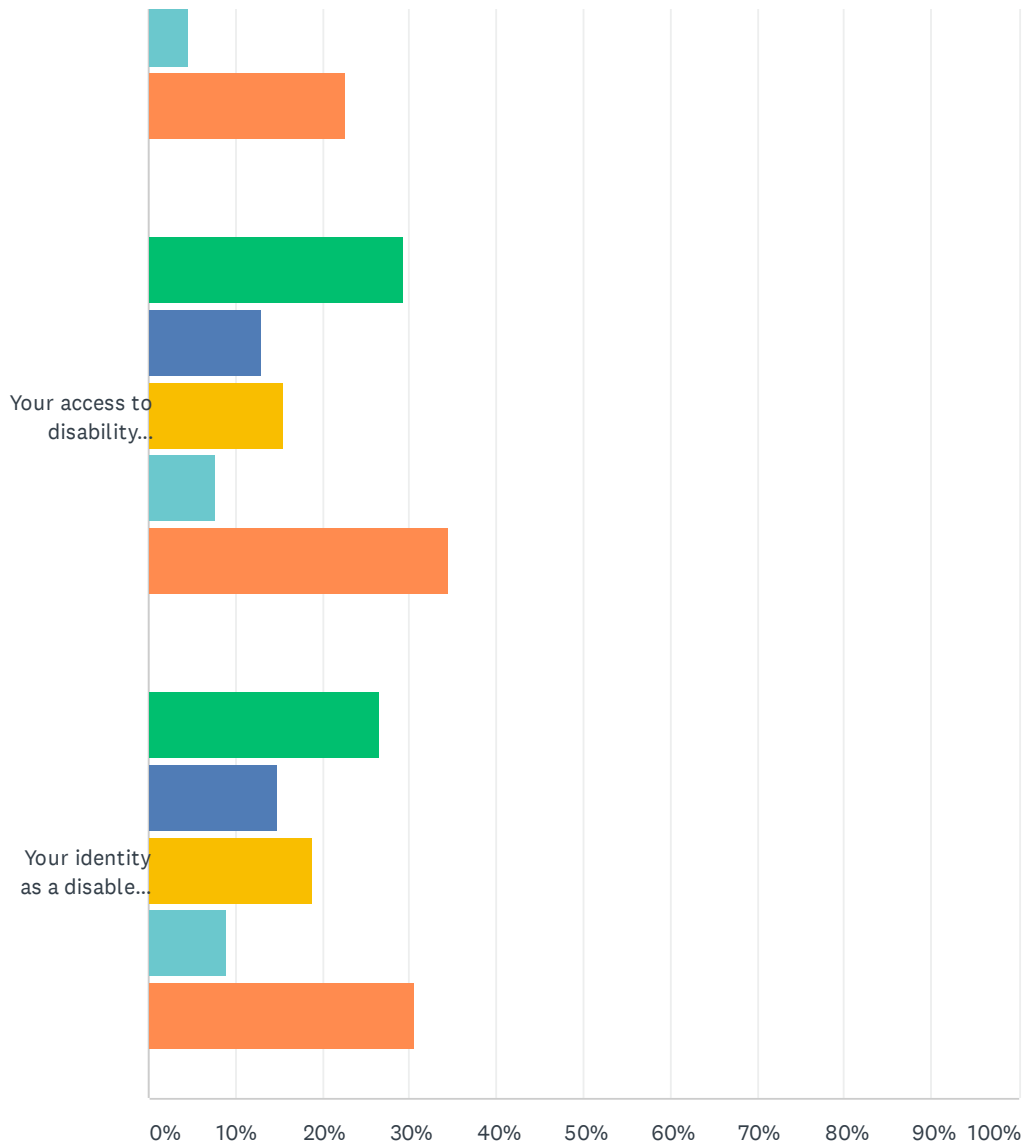


ANSWER CHOICES	RESPONSES	
A General Practitioner (GP)	90.67%	136
A specialist doctor	32.67%	49
A social care professional	11.33%	17
Other (please specify)	10.67%	16
Total Respondents: 150		

Q27 Has your experience of being disbelieved by a health or care professional had a negative impact in any of the following areas?

Answered: 157 Skipped: 23





■ Yes, a lot
 ■ Yes, a little
 ■ No
 ■ Not sure
 ■ Not applicable

	YES, A LOT	YES, A LITTLE	NO	NOT SURE	NOT APPLICABLE	TOTAL	WEIGHTED AVERAGE
Your self esteem	72.73% 112	17.53% 27	3.90% 6	2.60% 4	3.25% 5	154	1.36
Your relationship with health and care providers	54.19% 84	31.61% 49	5.81% 9	4.52% 7	3.87% 6	155	1.58
Your relationship with friends and family	25.32% 39	35.06% 54	28.57% 44	3.90% 6	7.14% 11	154	1.93
Your relationship with an employer	19.35% 30	23.23% 36	30.32% 47	4.52% 7	22.58% 35	155	2.30
Your access to disability benefits and services	29.22% 45	12.99% 20	15.58% 24	7.79% 12	34.42% 53	154	2.47
Your identity as a disabled person	26.62% 41	14.94% 23	18.83% 29	9.09% 14	30.52% 47	154	2.44

**Q28 If you wish you can tell us more about your experiences of being
disbelieved in relation to:1) your self esteem**

Answered: 78 Skipped: 102

Q29 2) your relationship with health and care providers

Answered: 81 Skipped: 99

Q30 3) your relationship with friends or family

Answered: 66 Skipped: 114

Q31 4) your relationship with an employer

Answered: 59 Skipped: 121

Q32 5) your access to disability benefits and services

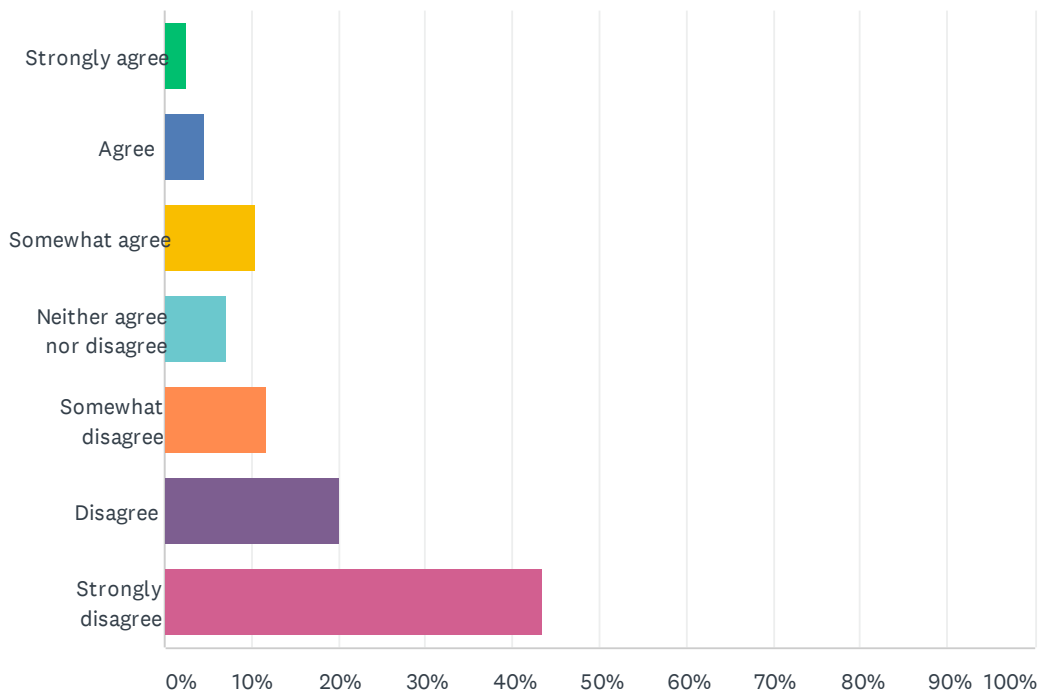
Answered: 61 Skipped: 119

Q33 6) your identity as a disabled person

Answered: 55 Skipped: 125

Q34 How much do you agree with the statement: "I feel supported by the services available for women with my health condition or disability"?

Answered: 154 Skipped: 26



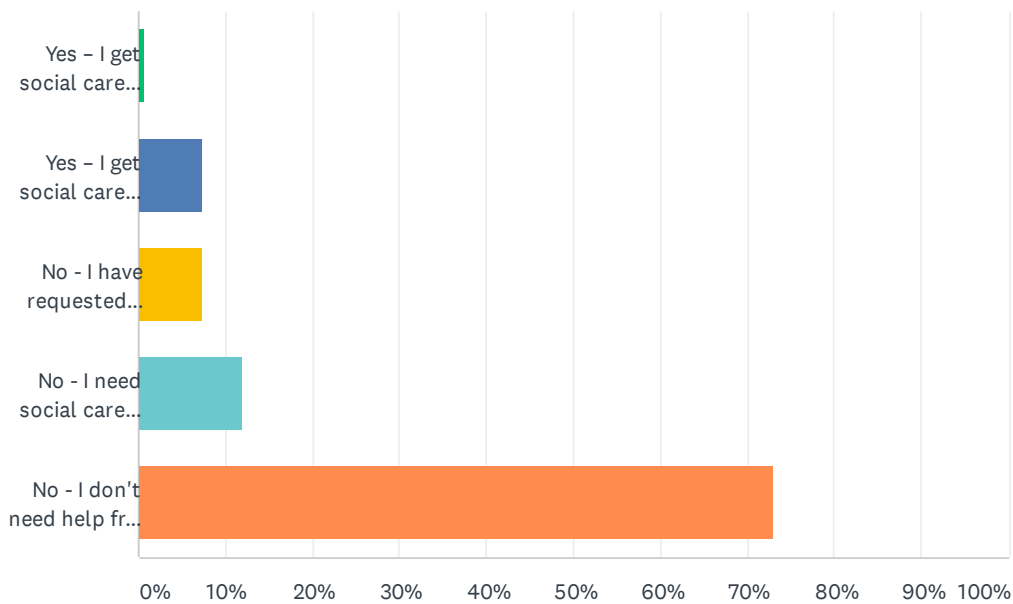
ANSWER CHOICES	RESPONSES	
Strongly agree	2.60%	4
Agree	4.55%	7
Somewhat agree	10.39%	16
Neither agree nor disagree	7.14%	11
Somewhat disagree	11.69%	18
Disagree	20.13%	31
Strongly disagree	43.51%	67
TOTAL		154

Q35 Would you like to share examples or provide suggestions as to how services can be improved for your specific condition or disability?

Answered: 112 Skipped: 68

Q36 This question is about what social care support you need and receive. Social care support is help provided by your local authority for daily living activities such as washing, dressing, feeding yourself, getting to appointments or parenting responsibilities. Have you been able to access the care and support you need from the social care system?

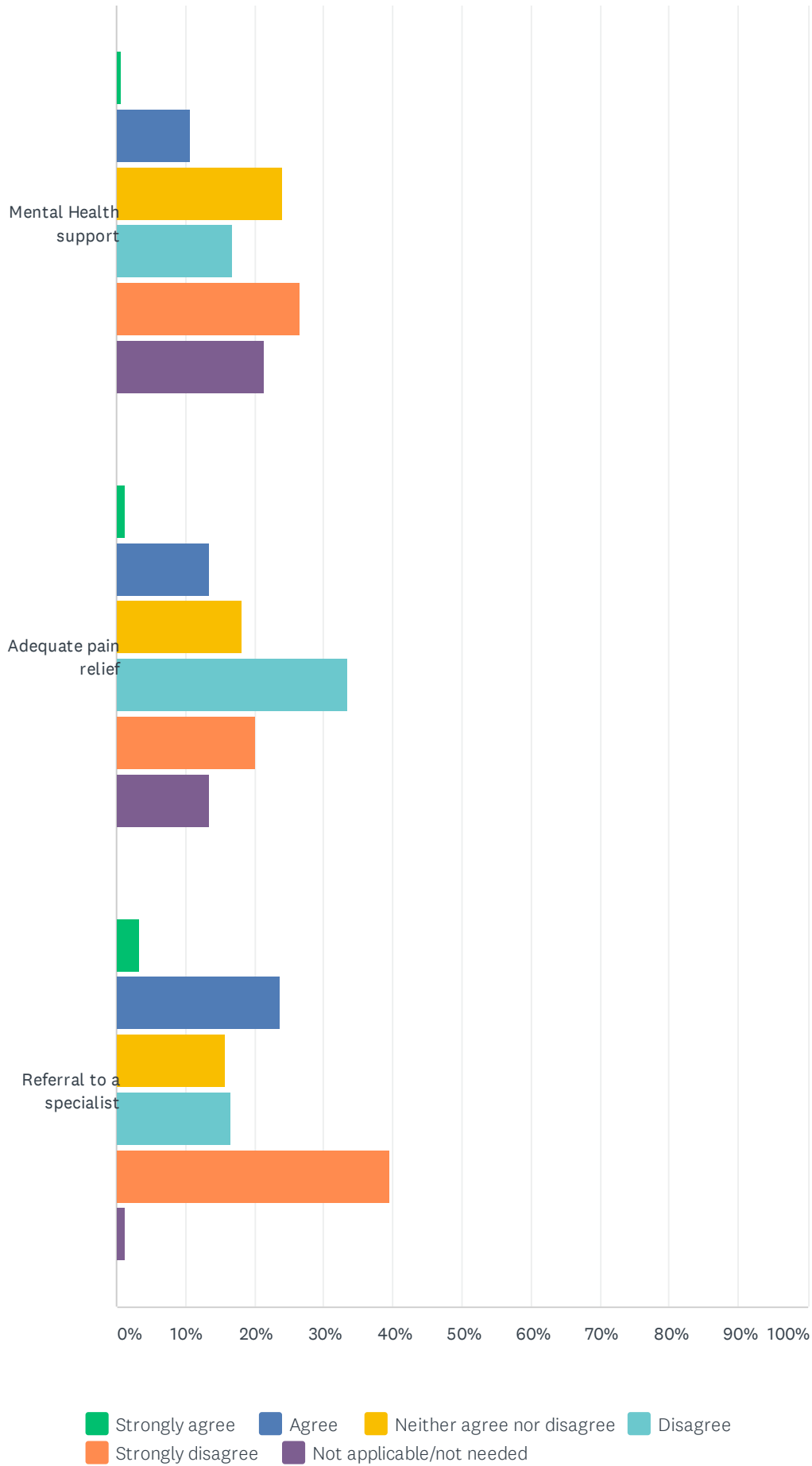
Answered: 152 Skipped: 28



ANSWER CHOICES	RESPONSES	
Yes – I get social care support that meets all my needs	0.66%	1
Yes – I get social care support that meets some of my needs	7.24%	11
No - I have requested social care support but was refused help	7.24%	11
No - I need social care support but have not requested it	11.84%	18
No - I don't need help from social care services	73.03%	111
TOTAL		152

Q37 How much do you agree with the statement: "I have received the help I needed" in relation to the following:

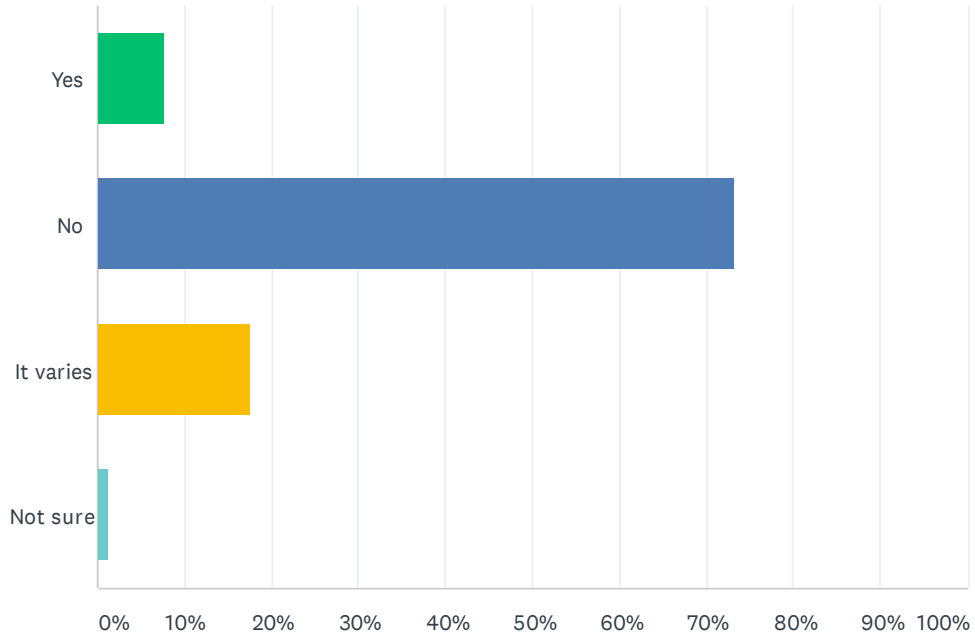
Answered: 153 Skipped: 27



	STRONGLY AGREE	AGREE	NEITHER AGREE NOR DISAGREE	DISAGREE	STRONGLY DISAGREE	NOT APPLICABLE/NOT NEEDED	TOTAL	WEIGHTED AVERAGE
Mental Health support	0.67% 1	10.67% 16	24.00% 36	16.67% 25	26.67% 40	21.33% 32	150	4.22
Adequate pain relief	1.34% 2	13.42% 20	18.12% 27	33.56% 50	20.13% 30	13.42% 20	149	3.98
Referral to a specialist	3.29% 5	23.68% 36	15.79% 24	16.45% 25	39.47% 60	1.32% 2	152	3.69

Q38 Do you consider yourself to be housebound or bedridden according to the above definition?

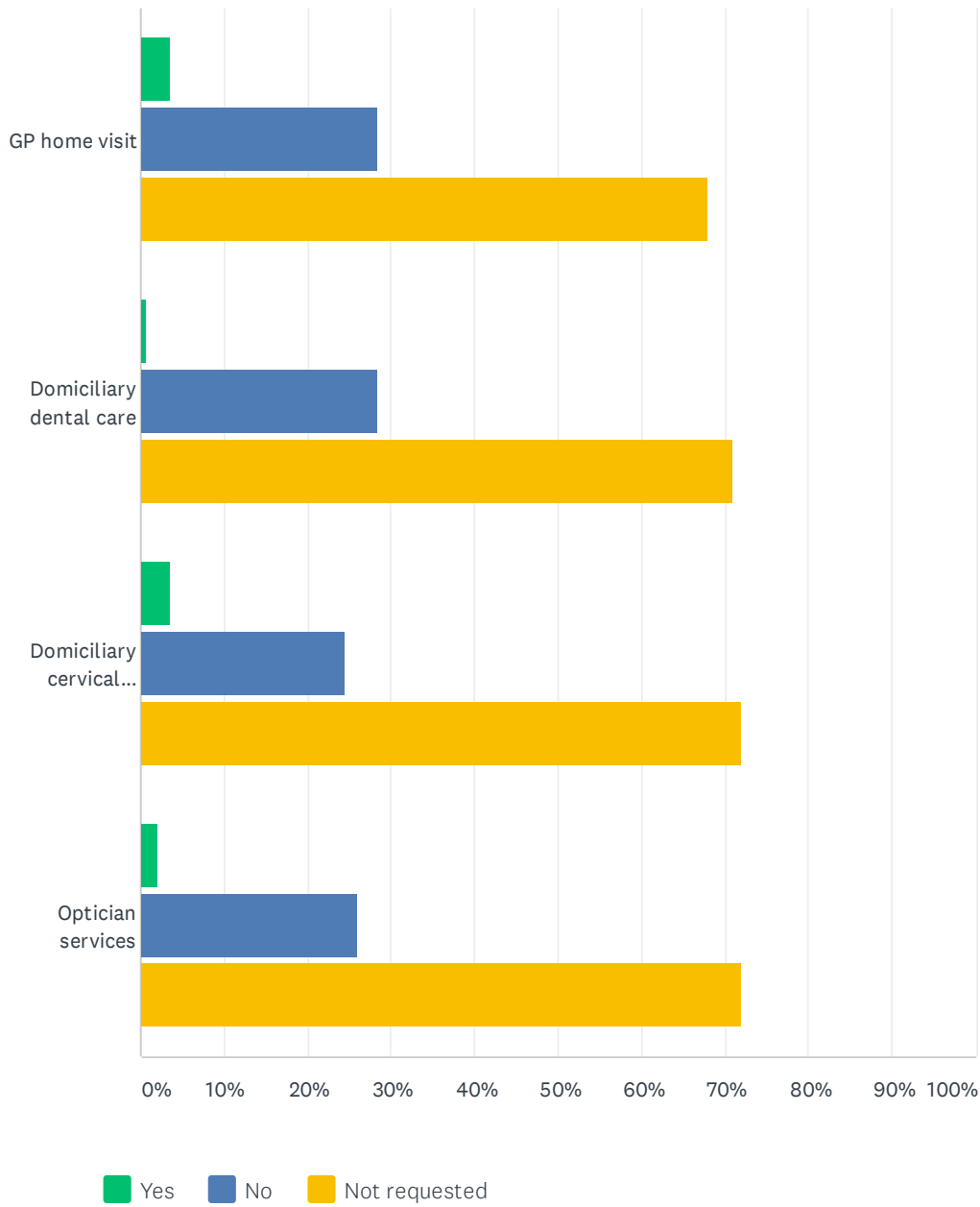
Answered: 153 Skipped: 27



ANSWER CHOICES	RESPONSES
Yes	7.84% 12
No	73.20% 112
It varies	17.65% 27
Not sure	1.31% 2
TOTAL	153

Q39 Have you received any of the following domiciliary services (at home) when requested?

Answered: 144 Skipped: 36



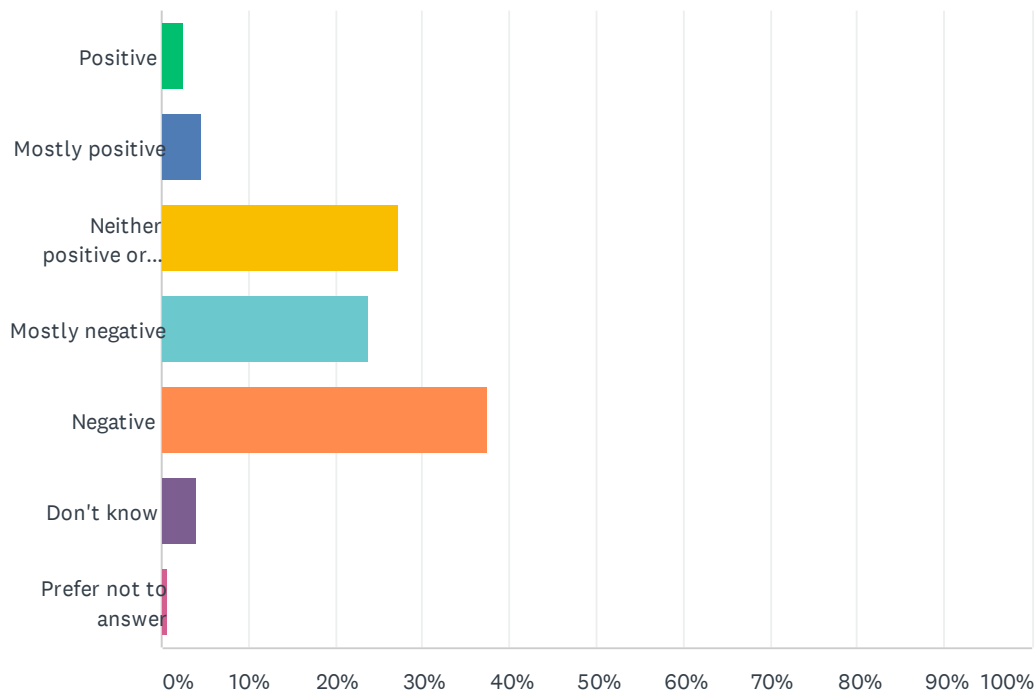
	YES	NO	NOT REQUESTED	TOTAL	WEIGHTED AVERAGE
GP home visit	3.47% 5	28.47% 41	68.06% 98	144	2.65
Domiciliary dental care	0.69% 1	28.47% 41	70.83% 102	144	2.70
Domiciliary cervical screening (smear test)	3.50% 5	24.48% 35	72.03% 103	143	2.69
Optician services	2.10% 3	25.87% 37	72.03% 103	143	2.70

Q40 Would you like to tell us about any experience of requesting or receiving domiciliary services? You can also use this box to tell us about any requests you have made for special arrangements or reasonable adjustments for hospital visits for procedures that can't be carried out at home.

Answered: 23 Skipped: 157

Q41 Do you feel that the COVID-19 pandemic has had a positive or negative effect on your health?

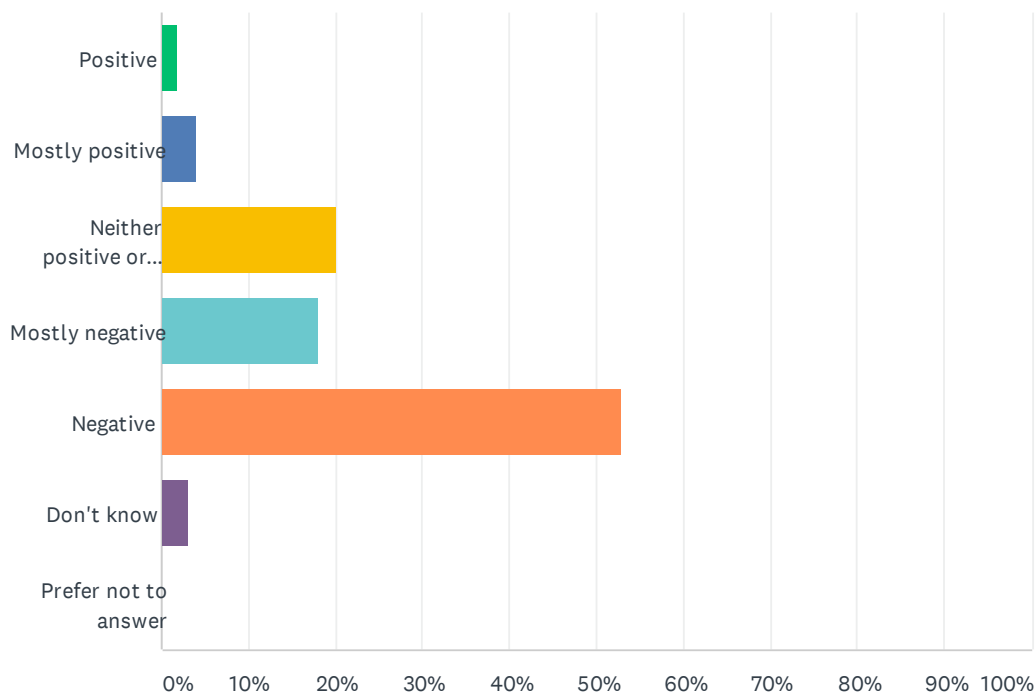
Answered: 155 Skipped: 25



ANSWER CHOICES	RESPONSES	
Positive	2.58%	4
Mostly positive	4.52%	7
Neither positive or negative	27.10%	42
Mostly negative	23.87%	37
Negative	37.42%	58
Don't know	3.87%	6
Prefer not to answer	0.65%	1
TOTAL		155

Q42 Do you feel that the COVID-19 pandemic has had a positive or negative effect on your ability to access healthcare services?

Answered: 155 Skipped: 25



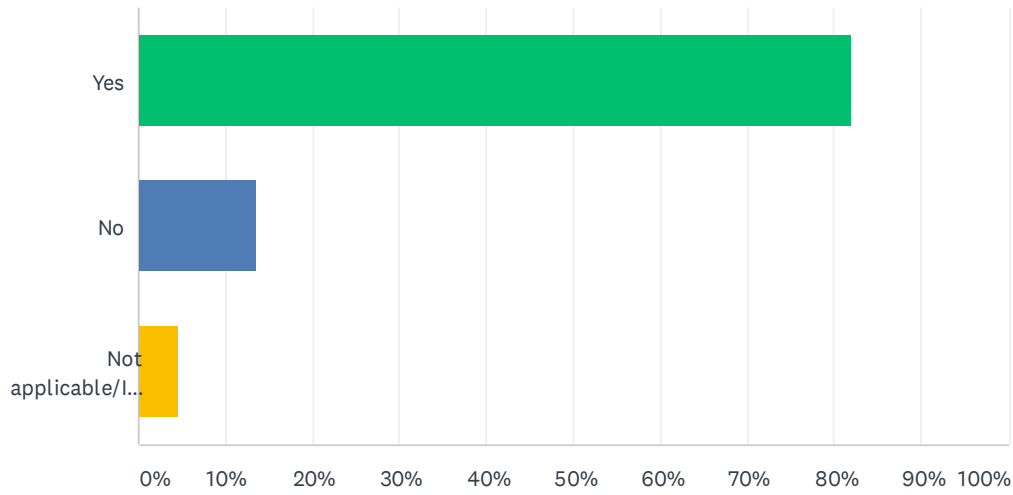
ANSWER CHOICES	RESPONSES	
Positive	1.94%	3
Mostly positive	3.87%	6
Neither positive or negative	20.00%	31
Mostly negative	18.06%	28
Negative	52.90%	82
Don't know	3.23%	5
Prefer not to answer	0.00%	0
TOTAL		155

Q43 Are there any aspects of healthcare have you particularly struggled to access during the COVID-19 pandemic?

Answered: 87 Skipped: 93

Q44 Have you been able to obtain a vaccine against Covid-19?

Answered: 155 Skipped: 25



ANSWER CHOICES	RESPONSES	
Yes	81.94%	127
No	13.55%	21
Not applicable/I have not wanted a vaccine	4.52%	7
TOTAL		155

Q45 Are there any service changes that you would like to see continued in the future?

Answered: 57 Skipped: 123

Q46 Is there anything you would like to share regarding research, evidence and data relating to women's health and healthcare?

Answered: 55 Skipped: 125