



**NeuroLifeNow
Analysis Report**

September 2021

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Foreword

As we write this, the UK Government has started to set out its plans for winter noting that NHS pressures might mean additional measures to restrict the spread of COVID-19 are put back in place.

Against this backdrop, pressures on services for people with neurological conditions are on the rise. As of July 2021, more than 5,500 people had been waiting for a neurology or neurosurgery appointment for more than a year. We are hearing from neurology specialists that they are facing a significant rise in referrals to their service in addition to the large backlog of appointments caused by the initial turmoil of the pandemic.

We are also observing a return to face to face services – for the first time, more than half of the appointments reported by NeuroLifeNow participants were delivered face to face.

Again, many of you told us you were feeling anxious, and reported delays to your care within the last 8 weeks. 14% of you said appointments had been cancelled in July and August. 46% said your mental health needs were being met to a small extent if at all.

If you need emotional or practical support then the Brain & Spine Foundation's free, national Helpline service is run by neuroscience-trained nurses who are here to help. The Helpline is a trusted safe space where you can seek ongoing support, clarity and reassurance. Call **0808 808 1000** (Mon-Thurs, 9am – 4pm) to speak to the Helpline, or email helpline@brainandspine.org.uk.

Your insight is being used to directly campaign for much needed support to improve services for people with neurological conditions. In the past few weeks alone we have shared experiences gathered via the platform with the former Minister for Mental Health, Nadine Dorries MP, and presented to an audience of more than 290 healthcare professionals providing mental health support for people with neurological conditions, as part of the Royal College of Psychiatrists NeuroPsychiatry Faculty Annual Meeting. The NHS England transformation team are using your experiences to inform forthcoming guidance on remote consultations in neurology, and numerous local services have requested access to data shared from people in their catchment area.

Thank you to all those who shared your thoughts on the App. We know that improvements are needed and as we embark on the next stage of development your feedback will directly influence how it evolves. And thank you for continuing to contribute through the survey. Your experiences are being heard by policymakers and you are driving positive change for the neurological community.

Marc Smith, CEO Brain and Spine Foundation
Georgina Carr, CEO Neurological Alliance (England)

Background

NeuroLifeNow is an App that supports people with neurological conditions to share experiences of their care in the last 8 weeks. In return, they can access news and information relevant to living with a neurological condition and professional support services run by the Brain & Spine Foundation. In as little as three weeks from closure of the questionnaire, respondents can review the experiences of other people with neurological conditions, too. The data in this report is based on responses received between 1 July – 31 August 2021. The full questionnaire and data tables are available in the appendices.

Key findings

- 201 people shared their experiences in July and August, with 79% female respondents and 20% male. 62 different neurological conditions and symptoms were represented in the survey. The top three conditions or symptoms represented were multiple sclerosis, functional neurological disorders and dystonia.
- Almost 1 in 5 of people felt their care was poor or very poor.
- 46% of respondents said their mental health needs were being met to a small extent or not at all. 65% of those who reported feeling anxious and/or hopeless reported that their mental health needs were being met to a small extent or not at all.
- Overall, 72% of the medical appointments evaluated were considered helpful. Of the reported appointments with a GP, 19% were not considered helpful.
- 54% of all appointments were delivered face to face, only 15% of which were considered unhelpful. 74% of appointments by videoconference were considered helpful.

Next steps

Your feedback is being used to make some immediate changes to the platform, including:

- Reviewing the questionnaire on a regular basis and incorporating feedback from people with neurological conditions
- Exploring options to gather and analyse 'qualitative' insight from people with neurological conditions – we hope to have this feature in place by November
- Reviewing how we communicate with the neurological community and the channels available to us to do so – this month, for the first time, users will receive this report direct to their email inbox.

We will also be presenting this data at the World Stroke Forum in October and at the Neurological Alliance's annual event 'NeuroFest', a conference for any organisation or individual interested in driving up standards in treatment, care and support.

Appendix 1: Questionnaire

Question	Hint	Answer 1	Answer 2	Answer 3	Answer 4	Answer 5	Answer 6	Answer 7	Answer 8	Answer 9	Answer10
Are you filling in this questionnaire for yourself?		Yes	No	I do not live with a neurological condition							
To what extent have you been following government rules on how to respond to the coronavirus?		Completely	To some extent	Not at all	Don't know						
Overall, do you think the government is relaxing coronavirus restrictions...		Too quickly	Too slowly	About the right speed							
Which of the following describes how you feel at the moment? Please tick all that apply		Calm	Well supported	Anxious	Hopeless	Lonely					
To what extent do you feel your mental health needs are being met?		To a great extent	To a moderate extent	To a small extent	Not at all	Don't know					

Thinking about your finances, how are you coping at the moment?		I have enough money to manage well	I have enough money to get by	I am struggling to cover my costs	I do not have enough money to cover my basic needs						
Have you accessed treatment, care or support for your neurological condition in the past 8 weeks?	This could include support from the NHS, care providers or charities	Yes	No								
Overall, how would you describe your experience of your health and care services in the last eight weeks?	Services could include contact with a health and care professional about treatment and support for your neurological condition. This could include contact by letter, phone, videoconference or face to face.	Very Good	Good	Average	Poor	Very Poor	Not applicable				
How many medical		0	1	2	3	4	5	6 or more			

appointments (including remote appointments) have you had in the last eight weeks?											
Who was your medical appointment with?	Tell us which health or care professional you had your first appointment in the last 4 weeks with	Neurologist	Specialist nurse	Physiotherapist	Speech and language therapist	Occupational therapist	Psychologist/Psychiatrist	GP	Social services	Neurosurgeon	Other (please specify)
Other (please specify)		Other (please specify)									
How was your medical appointment delivered?	Tell us how you spoke with your medical professional	Phone	Videconference	Via text/WhatsApp	Face to face	Other (please specify)					
Other (please specify)		Other (please specify)									
How helpful was your medical appointment?		It was helpful	It was not helpful	Don't know							
Have any of your medical appointments or procedures been cancelled	This refers to procedures or appointments that have been cancelled and	Yes	No	Don't know							

in the last 8 weeks?	you do not know when they have been rescheduled until										
Which appointments or procedures have been cancelled? Please tick all that apply		A drug therapy appointment	A routine appointment with a neurologist	A first appointment with a neurologist	An appointment with a specialist nurse	Diagnostic tests	An appointment for surgery	An appointment with a psychologist or psychiatrist	A physiotherapy appointment	A GP appointment	Other (please specify)
Other (please specify)											
Have any of your medical appointments or procedures been delayed in the last 8 weeks?	This refers to procedures or appointments that have been delayed and a new date has been set for them to go ahead	Yes	No	Don't know							
Which appointments have been delayed? Please tick all that apply		A drug therapy appointment	A routine appointment with a neurologist	A first appointment with a neurologist	An appointment with a specialist nurse	Diagnostic tests	An appointment for surgery	An appointment with a psychologist or psychiatrist	A physiotherapy appointment	A GP appointment	Other (please specify)

Other (please specify)		Other (please specify)									
Overall, approximately how long have your appointments been delayed until?		Less than 1 month	1 - 2 months	3 - 6 months	6 - 12 months	More than a year	I do not know				
How many times have you sought A&E/emergency support from the NHS as a result of your neurological condition in the last 8 weeks?		0	1- 2 times	3 - 5 times	6 or more times						
Overall, do you feel that your experience of emergency care was different during the COVID-19 pandemic compared to before the pandemic?		It was better	It was the same	It was worse							
Please tell us why											

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Demographics

Figure 1: Gender of respondents

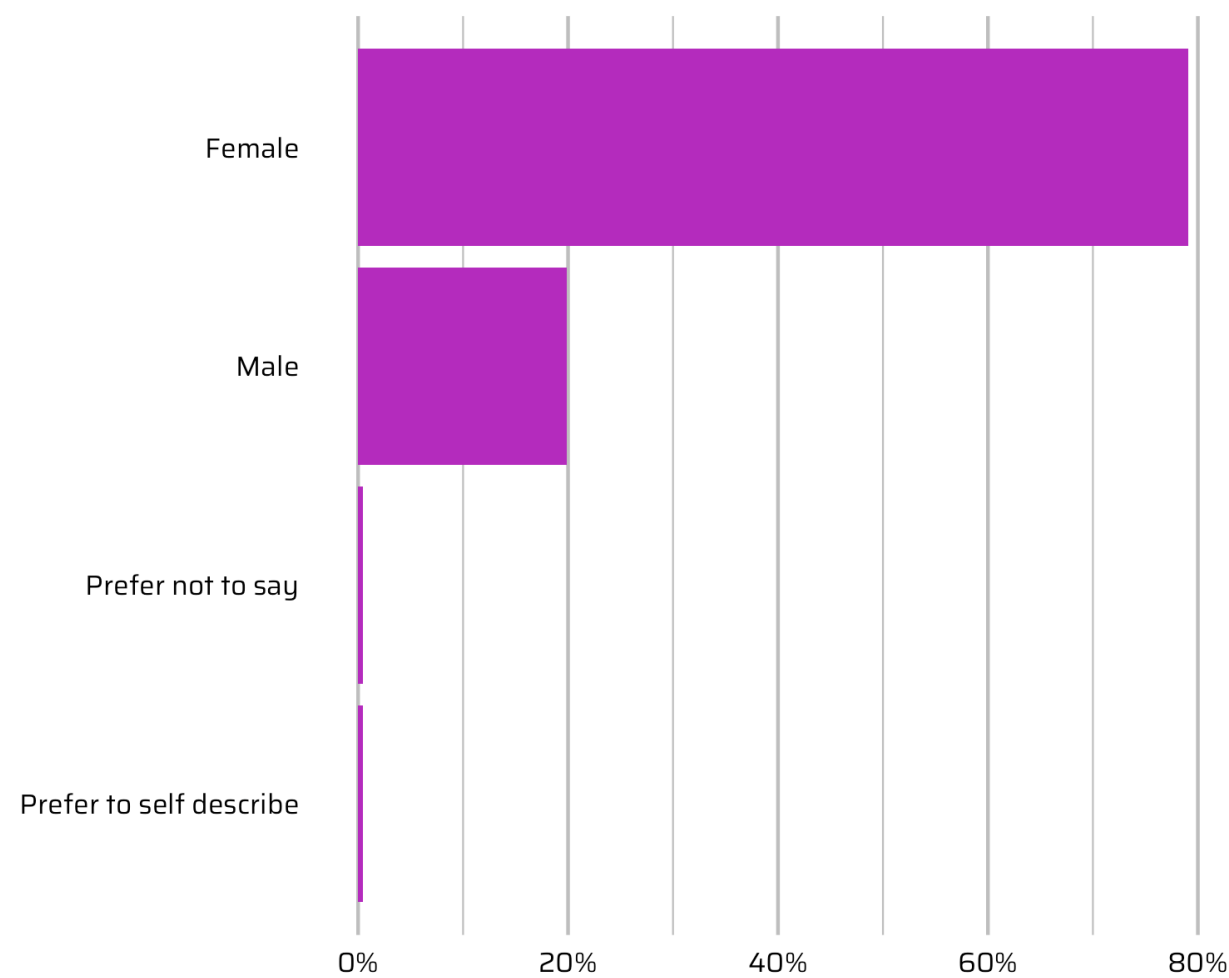


Table 1: Gender of respondents

Gender	Respondents	Percentage
Female	159	79
Male	40	20
Prefer not to say	1	0
Prefer to self describe	1	0

Figure 2: Age of respondents

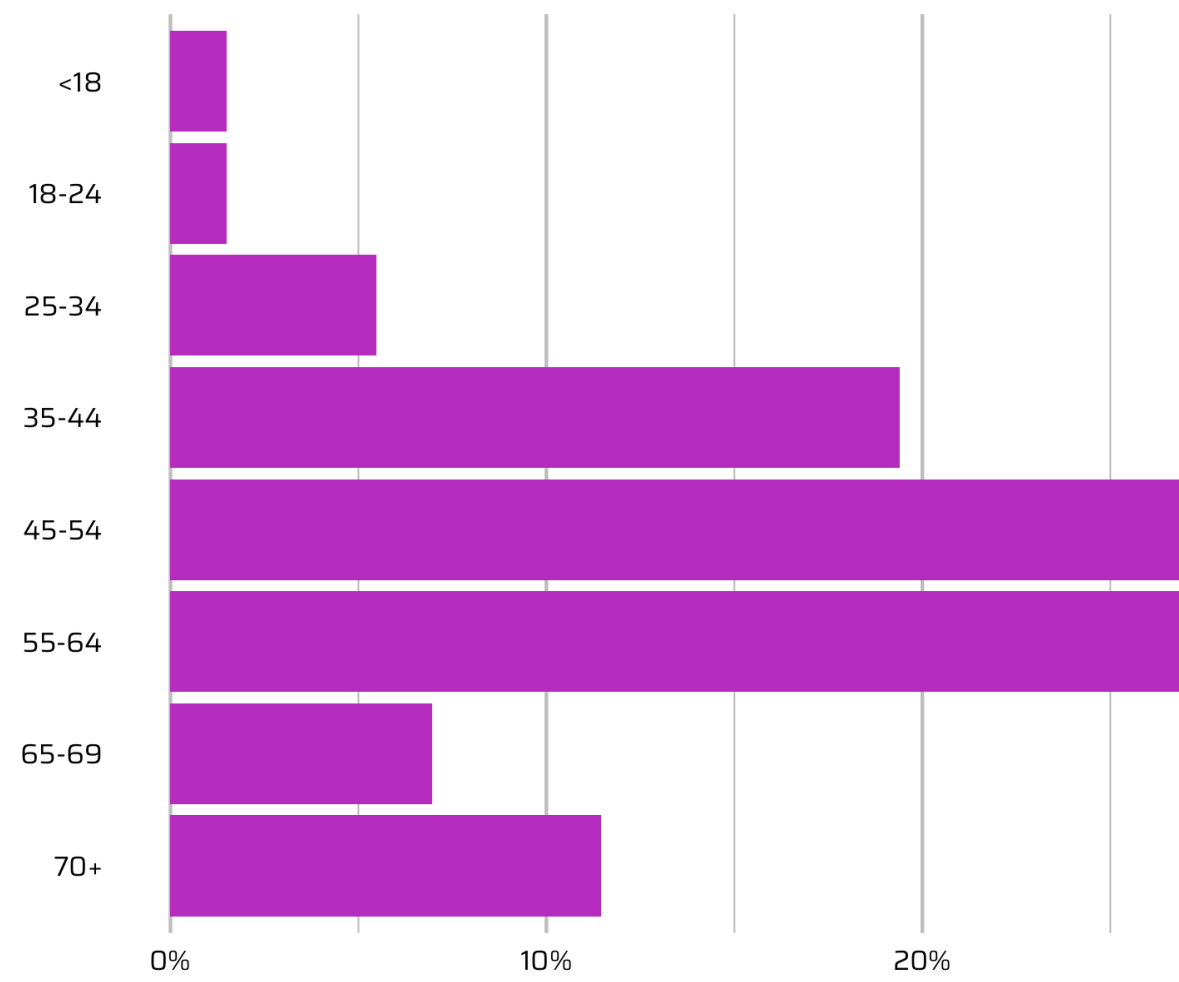


Table 2: Age of respondents

Age	Respondents	Percentage
<18	3	1
18-24	3	1
25-34	11	5
35-44	39	19
45-54	54	27
55-64	54	27
65-69	14	7
70+	23	11

Figure 3: Marital status of respondents

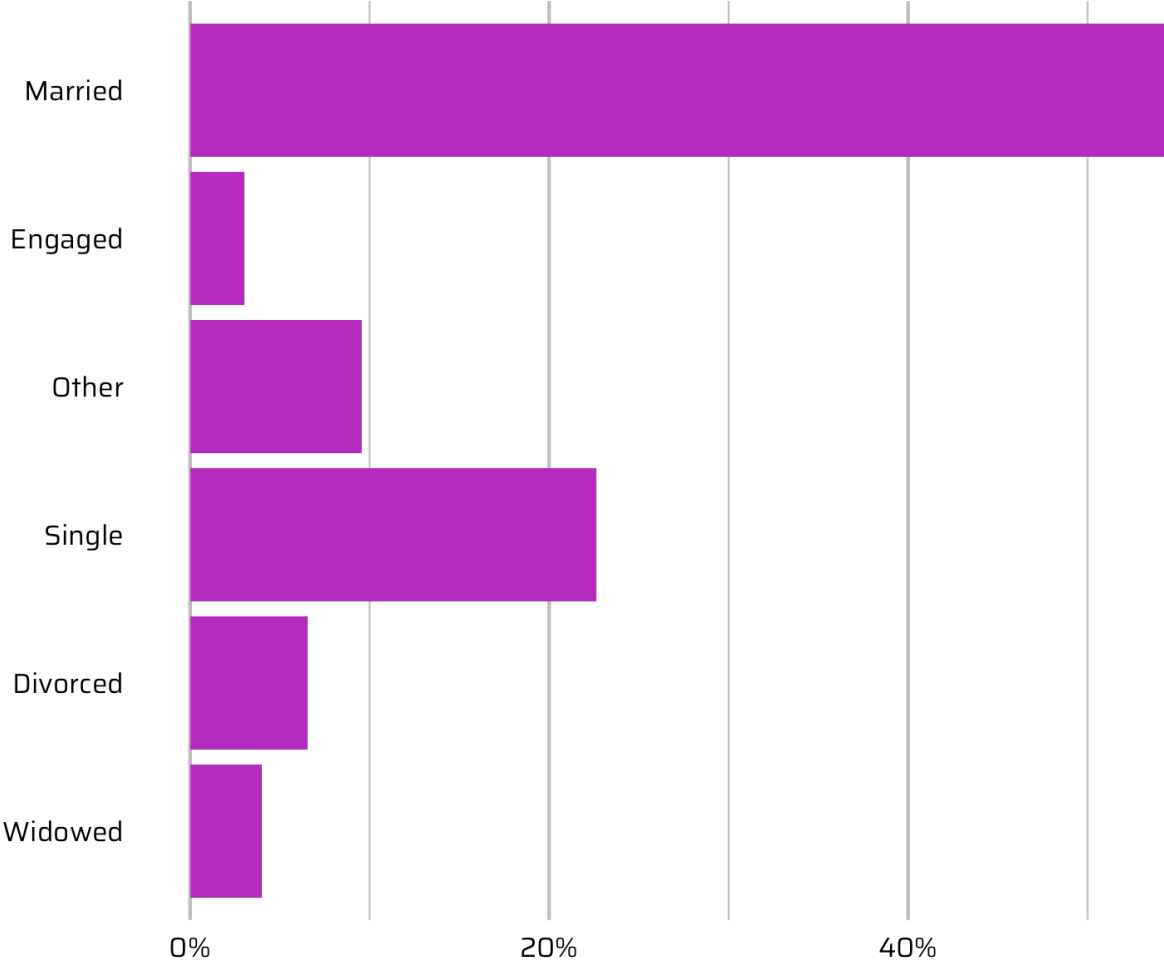


Table 3: Marital status of respondents

Marital Status	Respondents	Percentage
Married	108	54
Engaged	6	3
Other	19	10
Single	45	23
Divorced	13	7
Widowed	8	4

Figure 4: Employment status of respondents

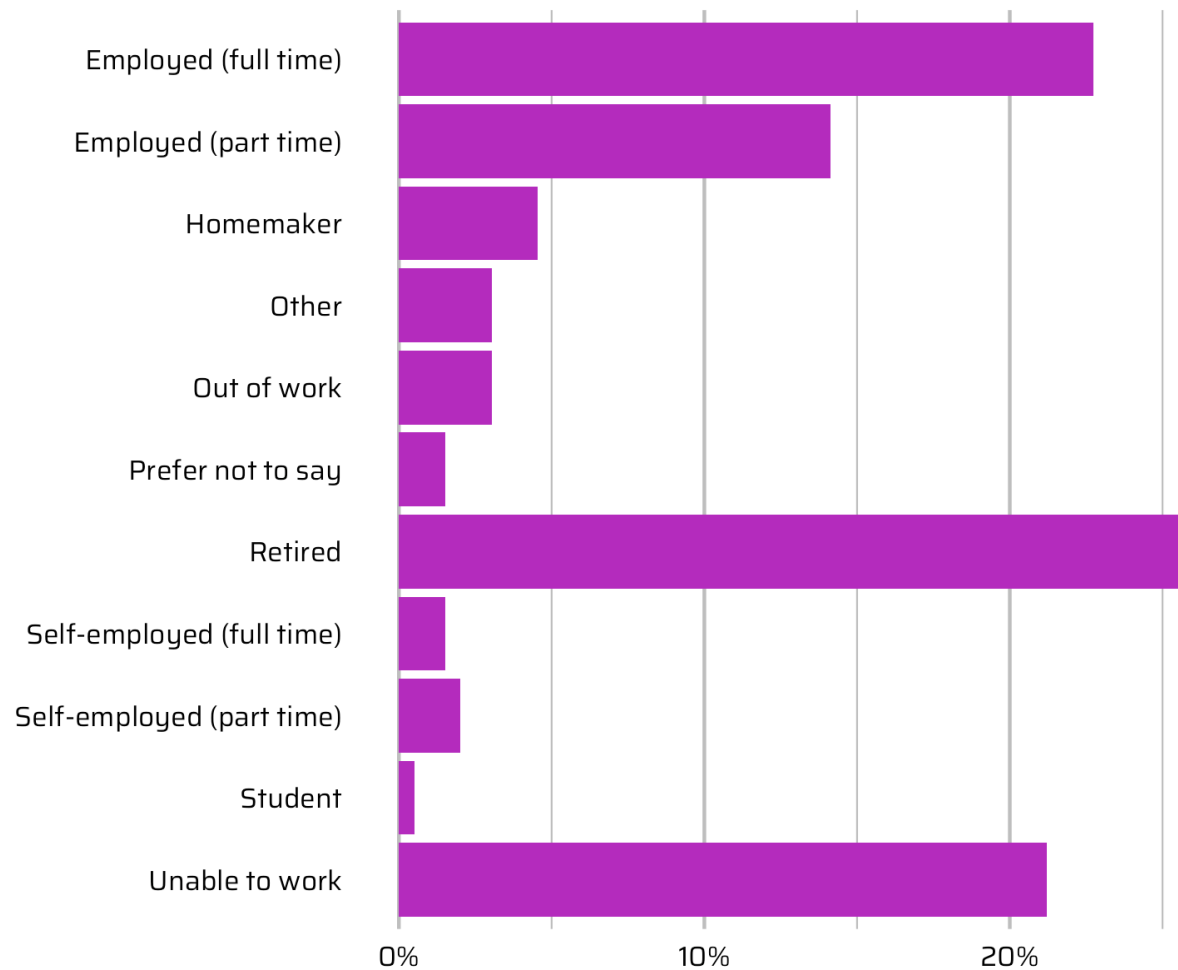


Table 4: Employment status of respondents

Employment Status	Respondents	Percentage
Employed (full time)	45	23
Employed (part time)	28	14
Homemaker	9	5
Other	6	3
Out of work	6	3
Prefer not to say	3	2
Retired	51	26
Self-employed (full time)	3	2
Self-employed (part time)	4	2
Student	1	1
Unable to work	42	21

Figure 5: Financial status of respondents

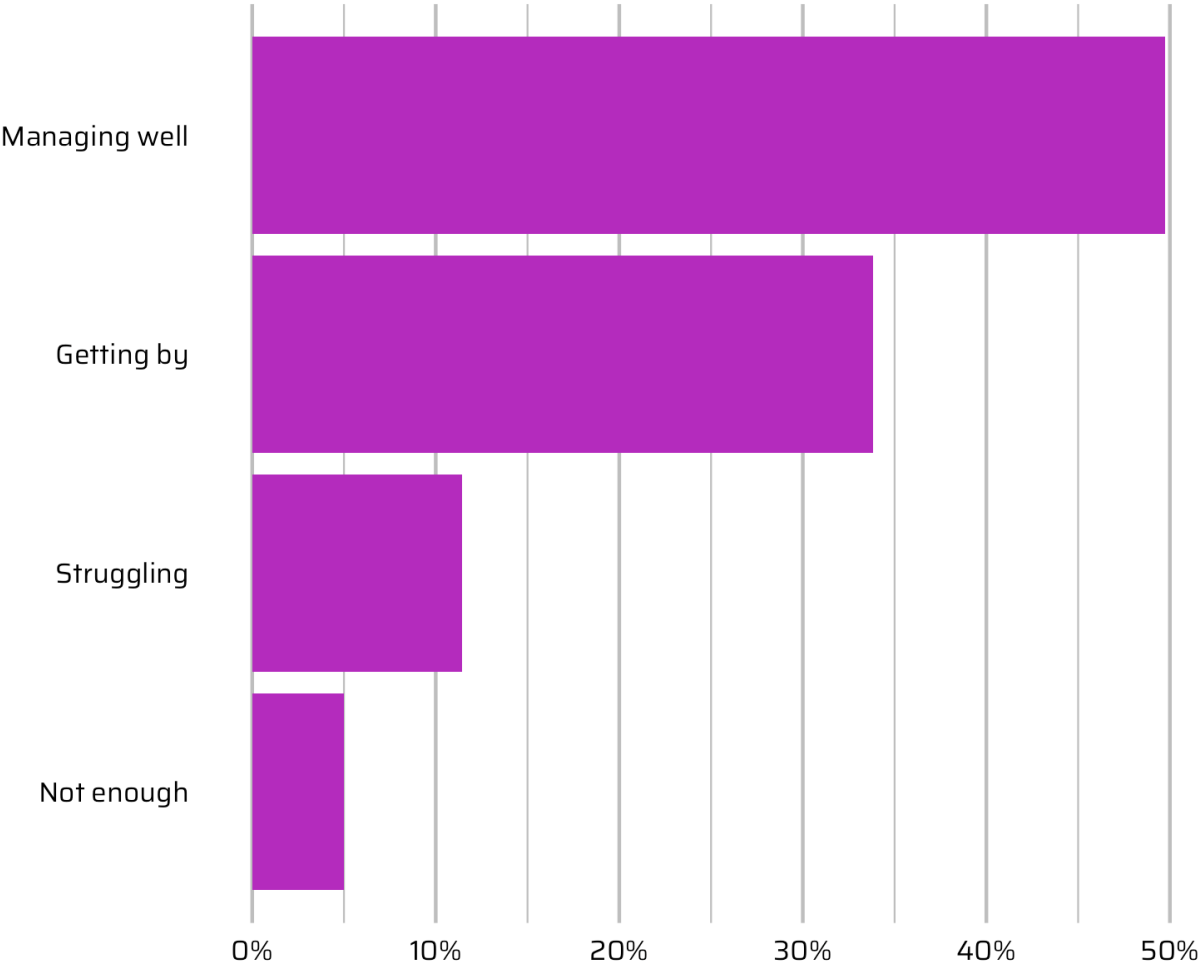


Table 5: Financial status of respondents

Financial Status	Respondents	Percentage
Managing well	100	50
Getting by	68	34
Struggling	23	11
Not enough	10	5

Figure 6: Extent to which respondents are following Government advice on COVID-19

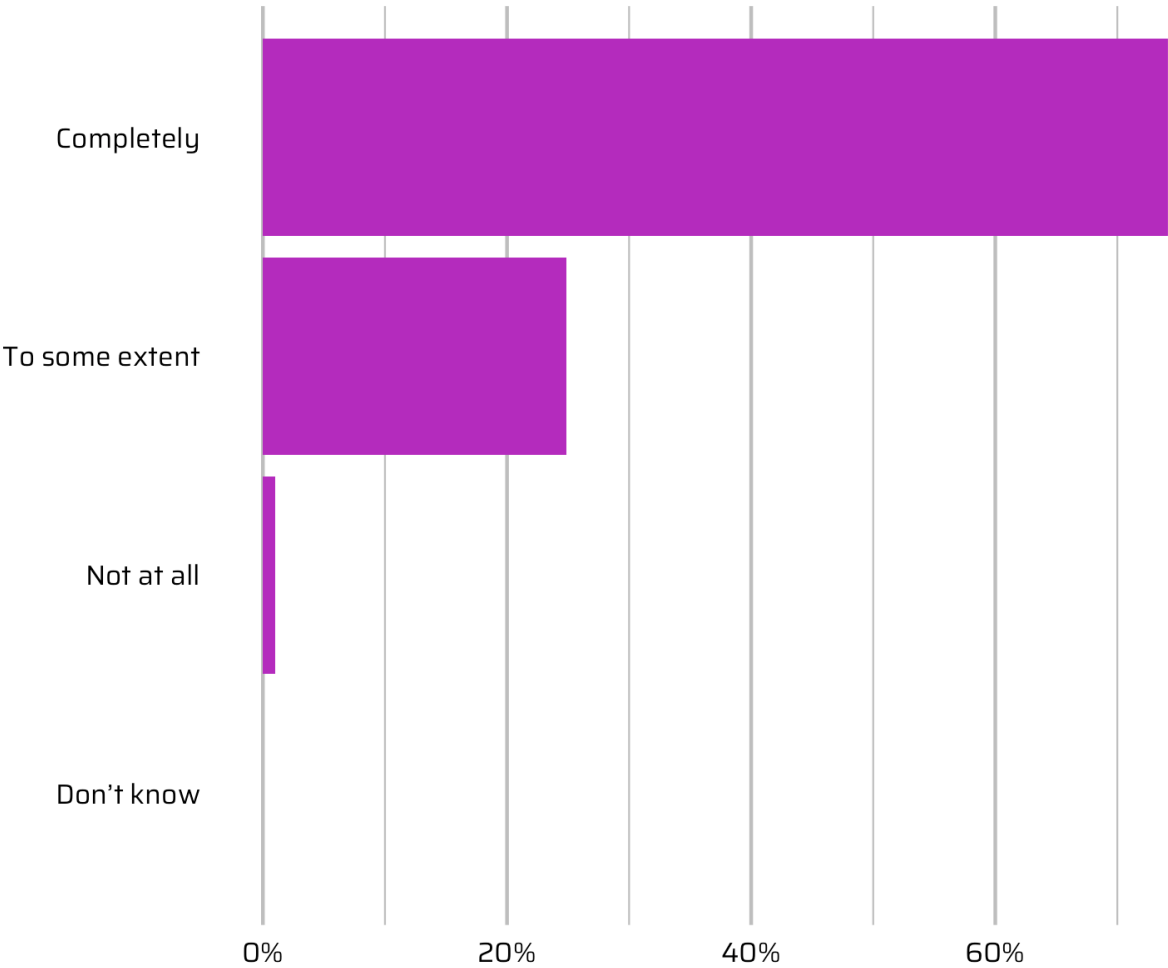


Table 6: Extent to which respondents are following Government advice on COVID-19

Following Advice	Respondents	Percentage
Completely	149	74
To some extent	50	25
Not at all	2	1
Don't know	0	0

Figure 7: Neurological conditions and symptoms

Nota bene: A single respondent may have multiple neurological conditions, therefore for this analysis the number of respondents per condition do not add up to the total number of respondents and the percentages do not add up to 100%.

A total of 78 respondents, equating to 39% of respondents, indicated that they have multiple neurological conditions.

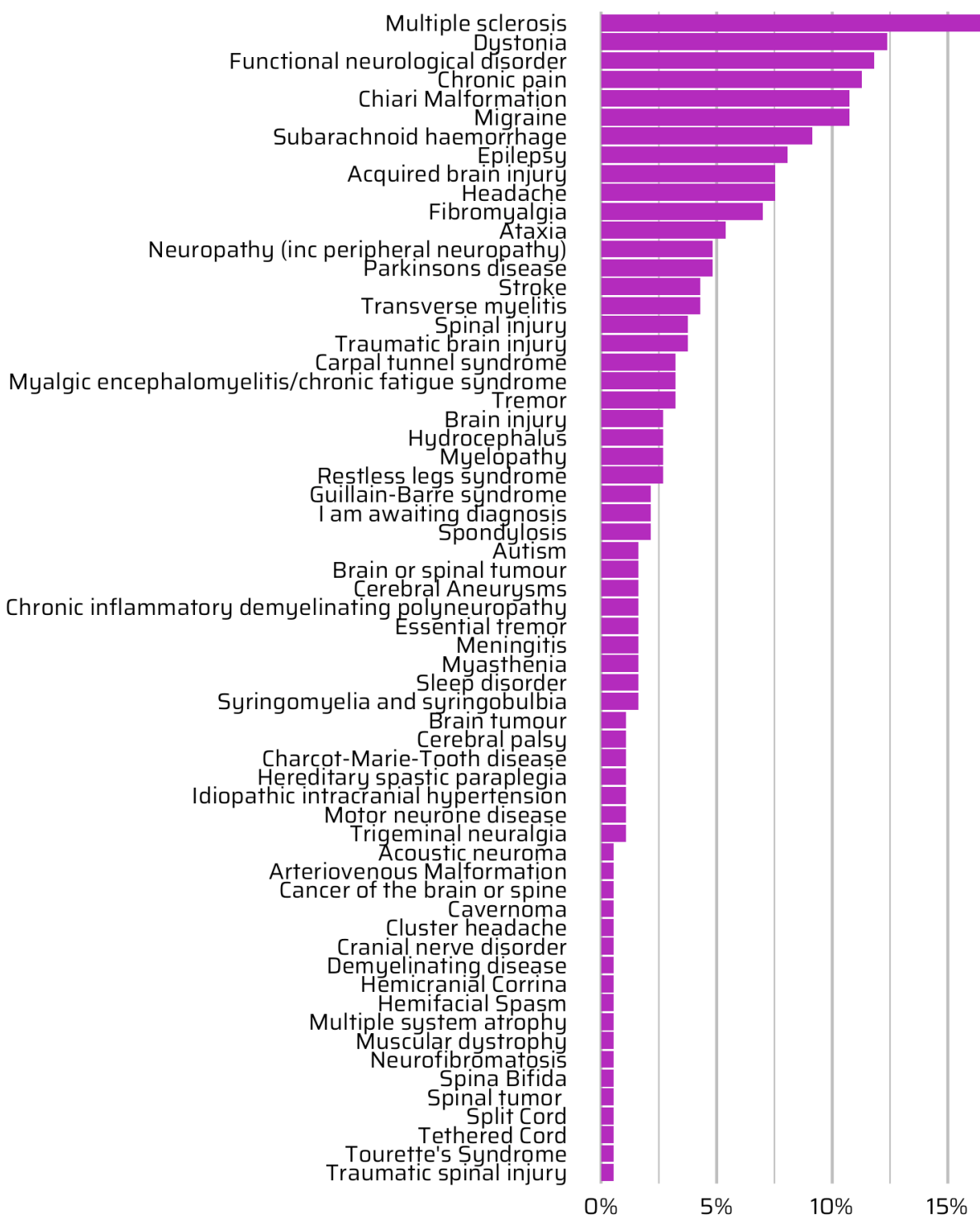


Table 7: Neurological conditions and symptoms

Condition	Respondents	Percentage
Multiple sclerosis	31	17
Dystonia	23	12
Functional neurological disorder	22	12
Chronic pain	21	11
Chiari Malformation	20	11
Migraine	20	11
Subarachnoid haemorrhage	17	9
Epilepsy	15	8
Acquired brain injury	14	8
Headache	14	8
Fibromyalgia	13	7
Ataxia	10	5
Neuropathy (inc peripheral neuropathy)	9	5
Parkinsons disease	9	5
Stroke	8	4
Transverse myelitis	8	4
Spinal injury	7	4
Traumatic brain injury	7	4
Carpal tunnel syndrome	6	3
Myalgic encephalomyelitis/chronic fatigue syndrome	6	3
Tremor	6	3
Brain injury	5	3
Hydrocephalus	5	3
Myelopathy	5	3
Restless legs syndrome	5	3
Guillain-Barre syndrome	4	2
I am awaiting diagnosis	4	2
Spondylosis	4	2
Autism	3	2
Brain or spinal tumour	3	2
Cerebral Aneurysms	3	2
Chronic inflammatory demyelinating polyneuropathy	3	2
Essential tremor	3	2
Meningitis	3	2
Myasthenia	3	2

Sleep disorder	3	2
Syringomyelia and syringobulbia	3	2
Brain tumour	2	1
Cerebral palsy	2	1
Charcot-Marie-Tooth disease	2	1
Hereditary spastic paraplegia	2	1
Idiopathic intracranial hypertension	2	1
Motor neurone disease	2	1
Trigeminal neuralgia	2	1
Acoustic neuroma	1	1
Arteriovenous Malformation	1	1
Cancer of the brain or spine	1	1
Cavernoma	1	1
Cluster headache	1	1
Cranial nerve disorder	1	1
Demyelinating disease	1	1
Hemicranial Corrina	1	1
Hemifacial Spasm	1	1
Multiple system atrophy	1	1
Muscular dystrophy	1	1
Neurofibromatosis	1	1
Spina Bifida	1	1
Spinal tumor	1	1
Split Cord	1	1
Tethered Cord	1	1
Tourette's Syndrome	1	1
Traumatic spinal injury	1	1

Figure 8: Ethnicity of respondents

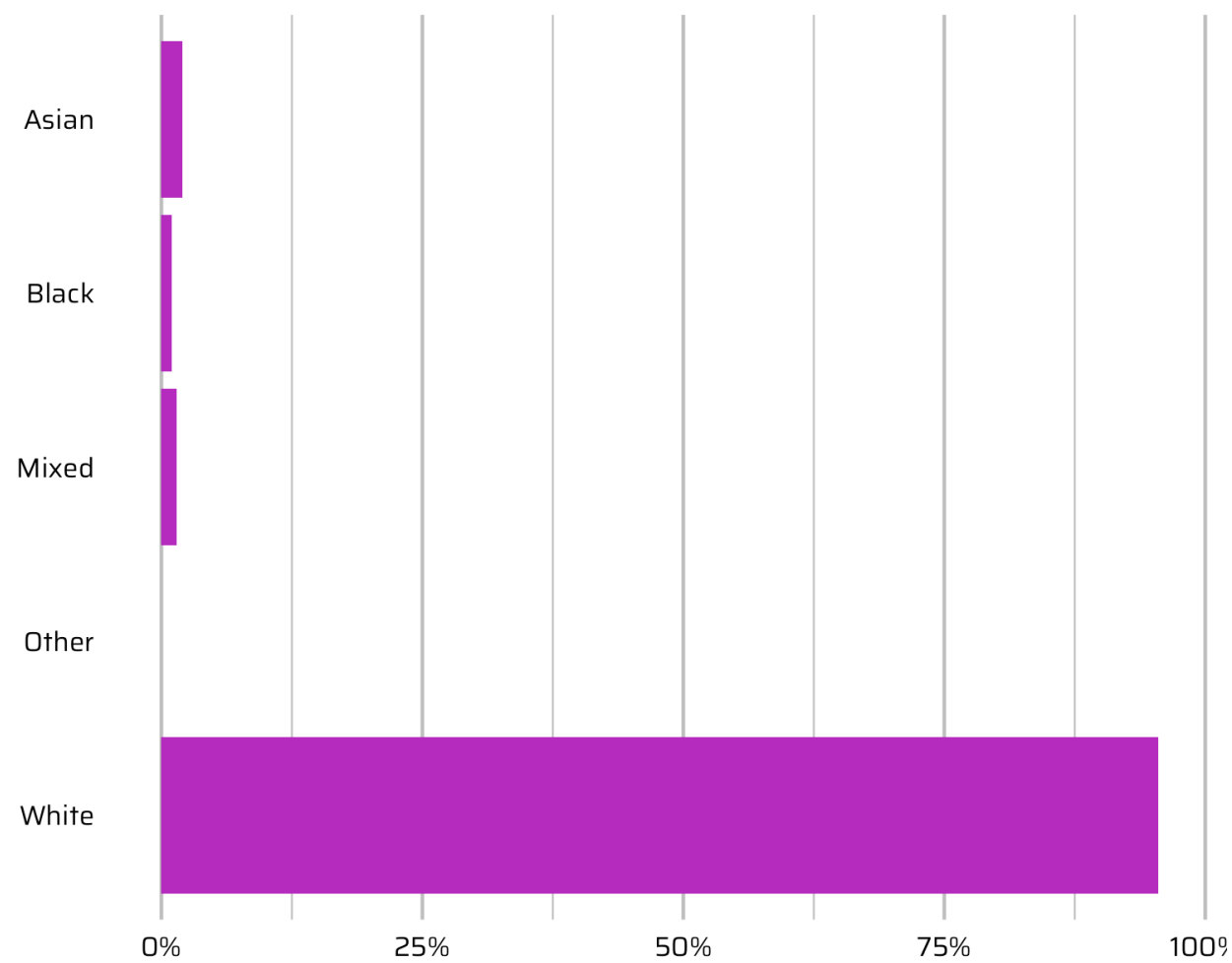


Table 8: Ethnicity of respondents

Ethnicity	Respondents	Percentage
Asian	4	2
Black	2	1
Mixed	3	1
Other	0	0
White	192	96

Figure 9: Evaluation of speed of lifting COVID-19 restrictions

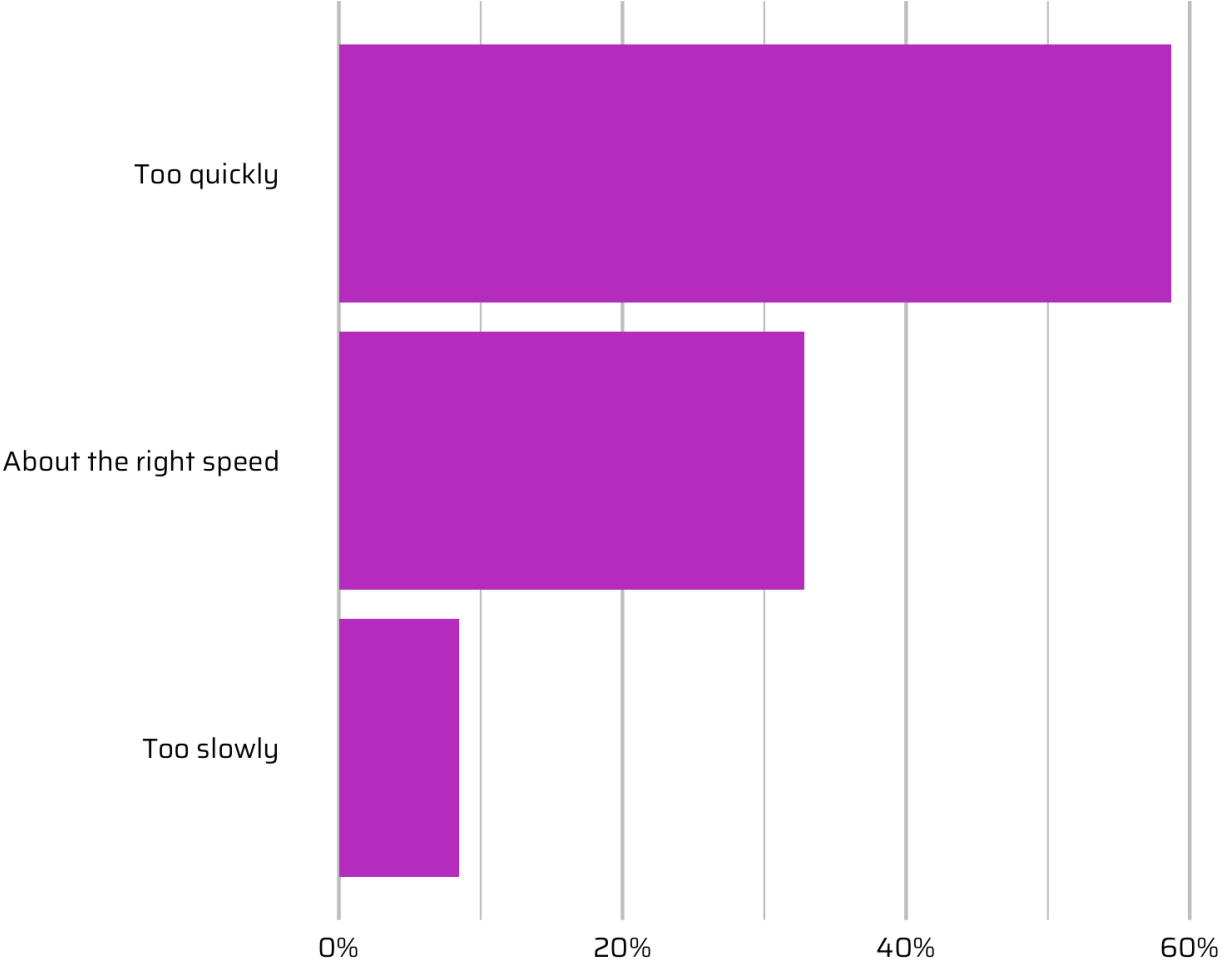


Table 9: Evaluation of speed of lifting COVID-19 restrictions

Speed	Respondents	Percentage
Too quickly	118	59
About the right speed	66	33
Too slowly	17	8

Experience Overall

Figure 10: Overall, what has your experience of care been like in the past 8 weeks?

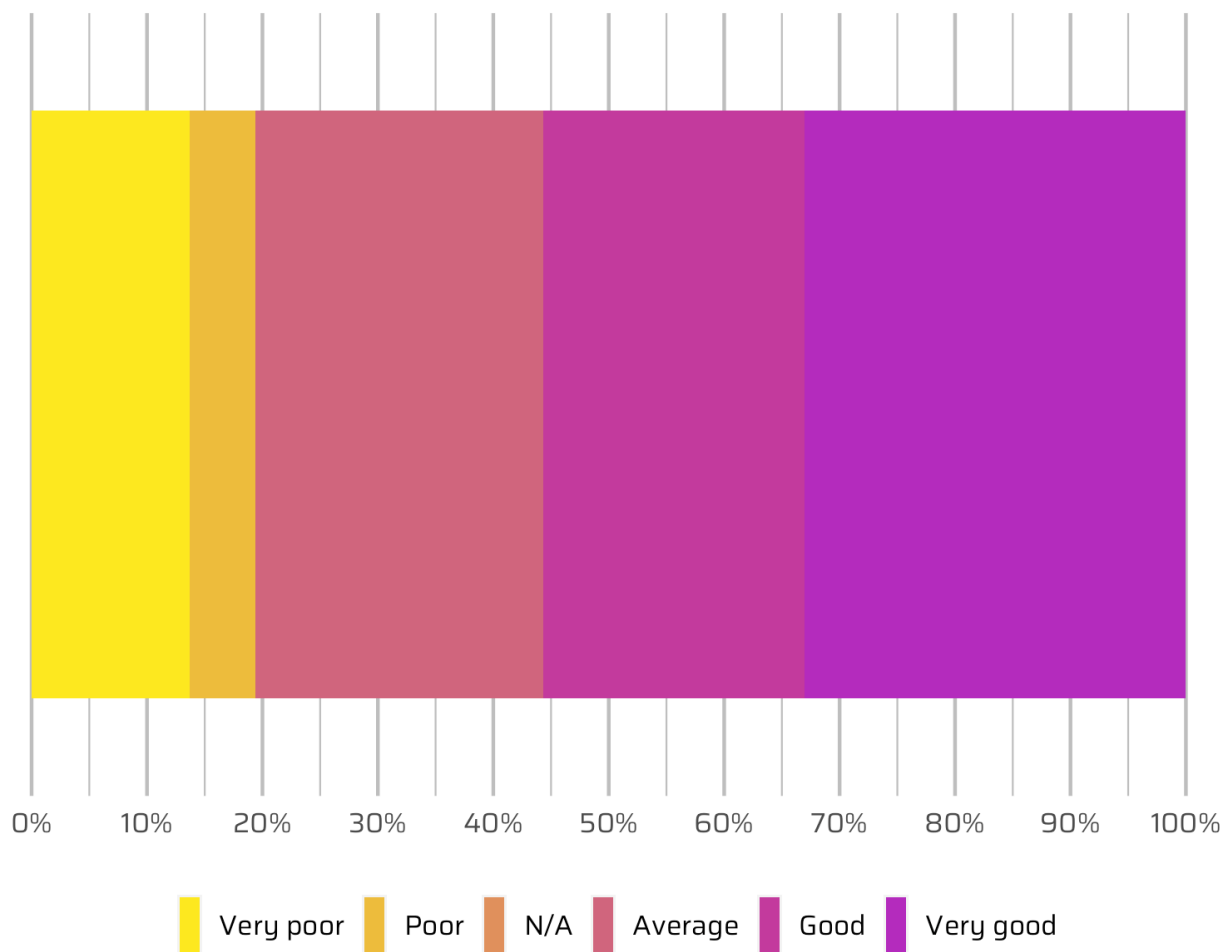


Table 10: No. of responses to the question 'Overall, what has your experience of care been like in the last 8 weeks?

Experience	Respondents	Percentage
Very good	41	33
Good	28	23
Average	31	25
N/A	0	0
Poor	7	6
Very poor	17	14

Figure 11: Experience of care by gender

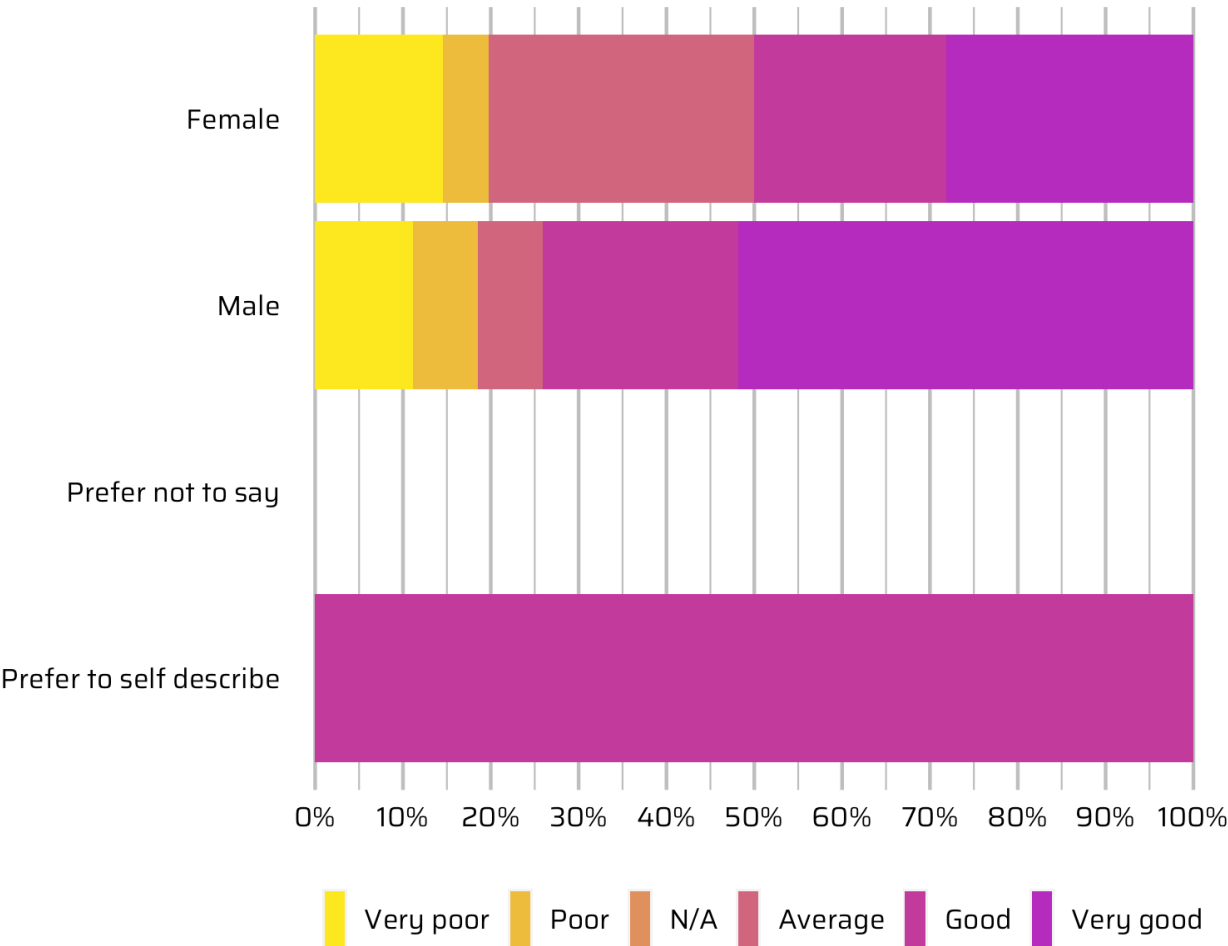


Table 11: No. of responses to the question 'Overall, what has your experience of care been like in the last 8 weeks?' by gender

Gender	Experience	Respondents	Percentage
Female	Very good	27	28
Female	Good	21	22
Female	Average	29	30
Female	N/A	0	0
Female	Poor	5	5
Female	Very poor	14	15
Male	Very good	14	52
Male	Good	6	22
Male	Average	2	7
Male	N/A	0	0
Male	Poor	2	7
Male	Very poor	3	11
Prefer not to say	Very good	0	NaN
Prefer not to say	Good	0	NaN
Prefer not to say	Average	0	NaN
Prefer not to say	N/A	0	NaN
Prefer not to say	Poor	0	NaN
Prefer not to say	Very poor	0	NaN
Prefer to self describe	Very good	0	0
Prefer to self describe	Good	1	100
Prefer to self describe	Average	0	0
Prefer to self describe	N/A	0	0
Prefer to self describe	Poor	0	0
Prefer to self describe	Very poor	0	0

Figure 12: Experience of care by employment status

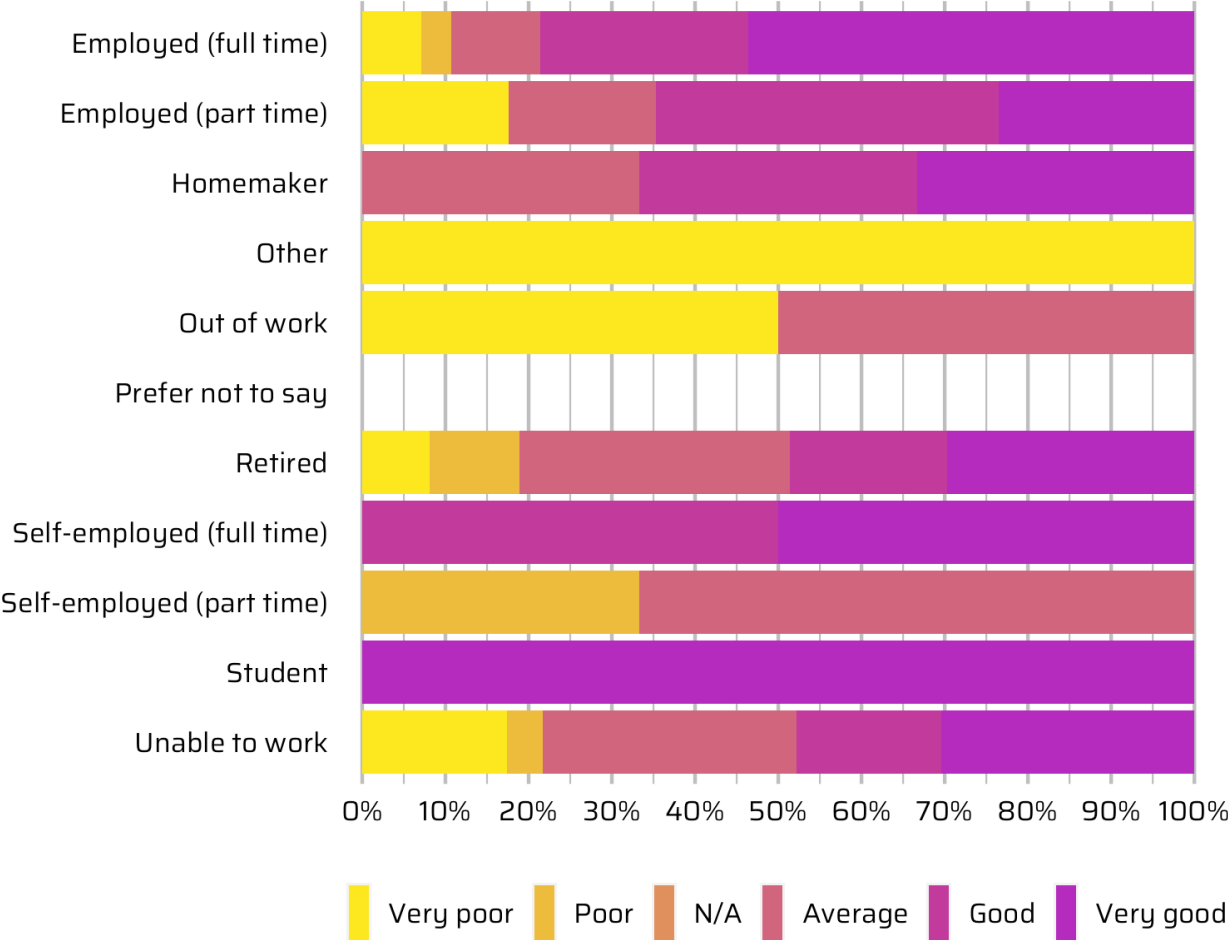


Table 12: No. of responses to the question 'Overall, what has your experience of care been like in the last 8 weeks?' by employment status

Employment Status	Experience	Respondents	Percentage
Employed (full time)	Very good	15	54
Employed (full time)	Good	7	25
Employed (full time)	Average	3	11
Employed (full time)	N/A	0	0
Employed (full time)	Poor	1	4
Employed (full time)	Very poor	2	7
Employed (part time)	Very good	4	24
Employed (part time)	Good	7	41
Employed (part time)	Average	3	18
Employed (part time)	N/A	0	0
Employed (part time)	Poor	0	0
Employed (part time)	Very poor	3	18
Homemaker	Very good	1	33
Homemaker	Good	1	33
Homemaker	Average	1	33
Homemaker	N/A	0	0
Homemaker	Poor	0	0
Homemaker	Very poor	0	0
Other	Very good	0	0
Other	Good	0	0
Other	Average	0	0
Other	N/A	0	0
Other	Poor	0	0
Other	Very poor	3	100
Out of work	Very good	0	0
Out of work	Good	0	0
Out of work	Average	2	50
Out of work	N/A	0	0
Out of work	Poor	0	0
Out of work	Very poor	2	50
Prefer not to say	Very good	0	NaN
Prefer not to say	Good	0	NaN
Prefer not to say	Average	0	NaN
Prefer not to say	N/A	0	NaN
Prefer not to say	Poor	0	NaN

Prefer not to say	Very poor	0	NaN
Retired	Very good	11	30
Retired	Good	7	19
Retired	Average	12	32
Retired	N/A	0	0
Retired	Poor	4	11
Retired	Very poor	3	8
Self-employed (full time)	Very good	1	50
Self-employed (full time)	Good	1	50
Self-employed (full time)	Average	0	0
Self-employed (full time)	N/A	0	0
Self-employed (full time)	Poor	0	0
Self-employed (full time)	Very poor	0	0
Self-employed (part time)	Very good	0	0
Self-employed (part time)	Good	0	0
Self-employed (part time)	Average	2	67
Self-employed (part time)	N/A	0	0
Self-employed (part time)	Poor	1	33
Self-employed (part time)	Very poor	0	0
Student	Very good	1	100
Student	Good	0	0
Student	Average	0	0
Student	N/A	0	0
Student	Poor	0	0
Student	Very poor	0	0
Unable to work	Very good	7	30
Unable to work	Good	4	17
Unable to work	Average	7	30
Unable to work	N/A	0	0
Unable to work	Poor	1	4
Unable to work	Very poor	4	17

Figure 13: Experience of care by number of dependents

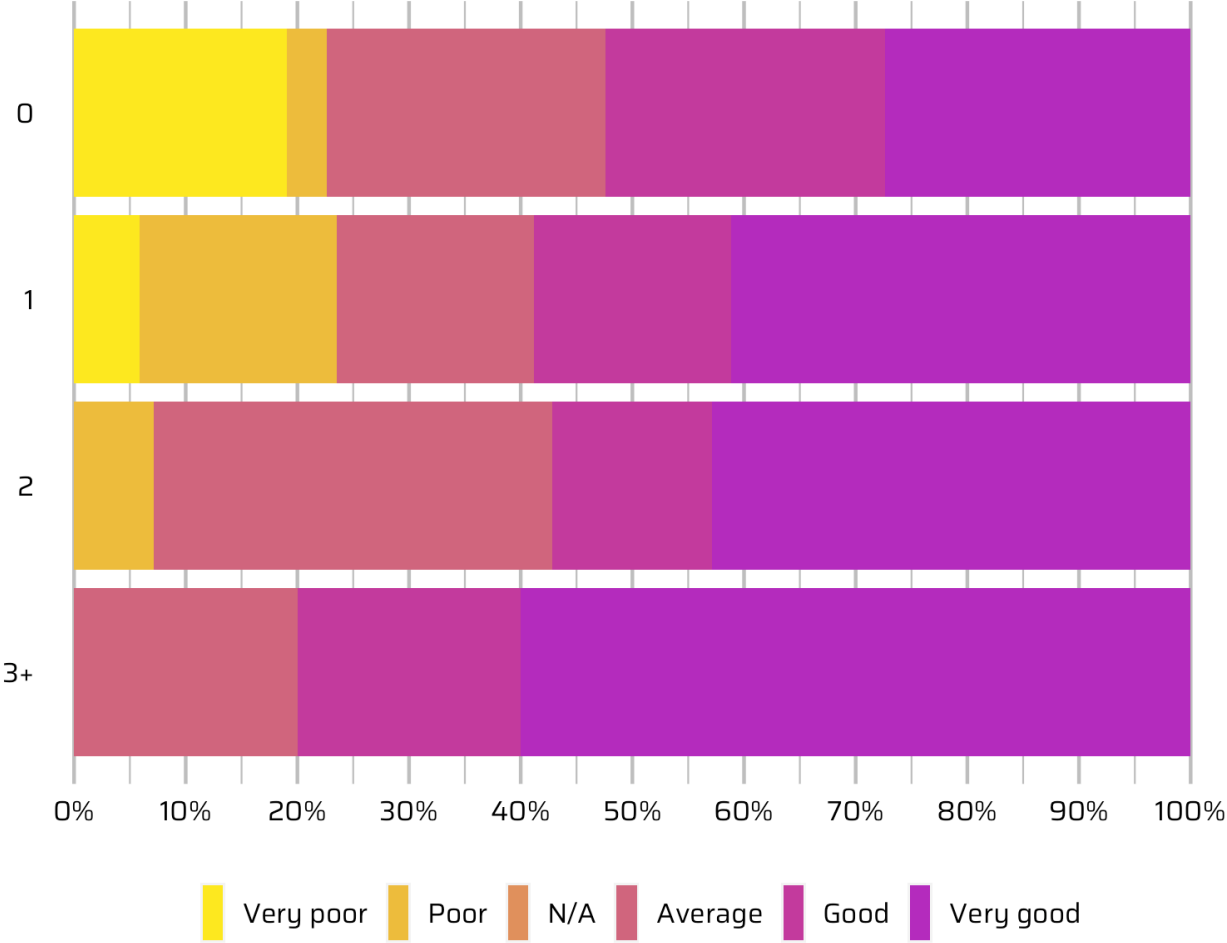


Table 13: No. of responses to the question 'Overall, what has your experience of care been like in the last 8 weeks?' by dependents

Dependents	Experience	Respondents	Percentage
0	Very good	23	27
0	Good	21	25
0	Average	21	25
0	N/A	0	0
0	Poor	3	4
0	Very poor	16	19
1	Very good	7	41
1	Good	3	18
1	Average	3	18
1	N/A	0	0
1	Poor	3	18
1	Very poor	1	6
2	Very good	6	43
2	Good	2	14
2	Average	5	36
2	N/A	0	0
2	Poor	1	7
2	Very poor	0	0
3+	Very good	3	60
3+	Good	1	20
3+	Average	1	20
3+	N/A	0	0
3+	Poor	0	0
3+	Very poor	0	0

Figure 14: Experience of care by marital status

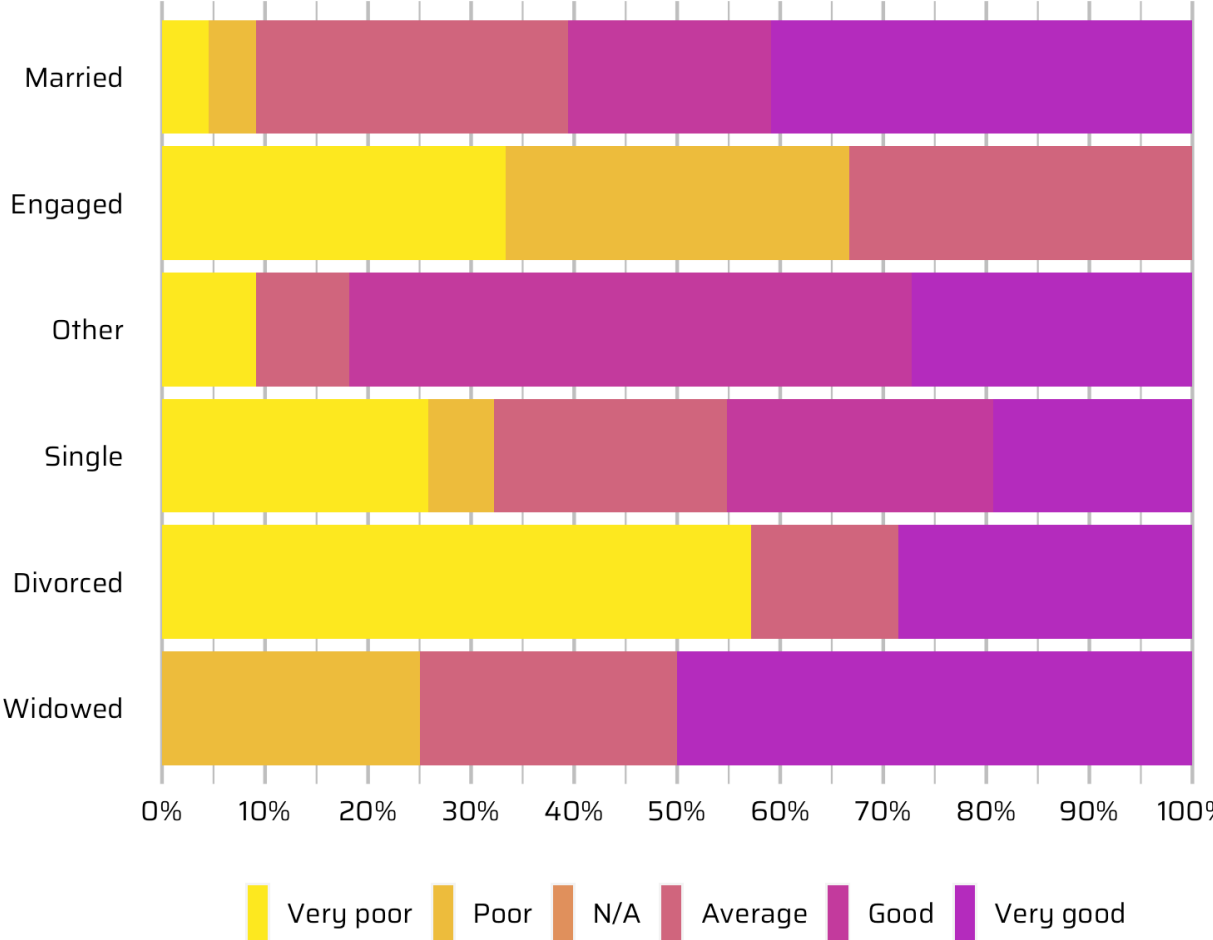


Table 14: No. of responses to the question 'Overall, what has your experience of care been like in the last 8 weeks?' by marital status

Marital Status	Experience	Respondents	Percentage
Married	Very good	27	41
Married	Good	13	20
Married	Average	20	30
Married	N/A	0	0
Married	Poor	3	5
Married	Very poor	3	5
Engaged	Very good	0	0
Engaged	Good	0	0
Engaged	Average	1	33
Engaged	N/A	0	0
Engaged	Poor	1	33
Engaged	Very poor	1	33
Other	Very good	3	27
Other	Good	6	55
Other	Average	1	9
Other	N/A	0	0
Other	Poor	0	0
Other	Very poor	1	9
Single	Very good	6	19
Single	Good	8	26
Single	Average	7	23
Single	N/A	0	0
Single	Poor	2	6
Single	Very poor	8	26
Divorced	Very good	2	29
Divorced	Good	0	0
Divorced	Average	1	14
Divorced	N/A	0	0
Divorced	Poor	0	0
Divorced	Very poor	4	57
Widowed	Very good	2	50
Widowed	Good	0	0
Widowed	Average	1	25
Widowed	N/A	0	0

Widowed	Poor	1	25
Widowed	Very poor	0	0

Figure 15: Experience of care and mental wellbeing

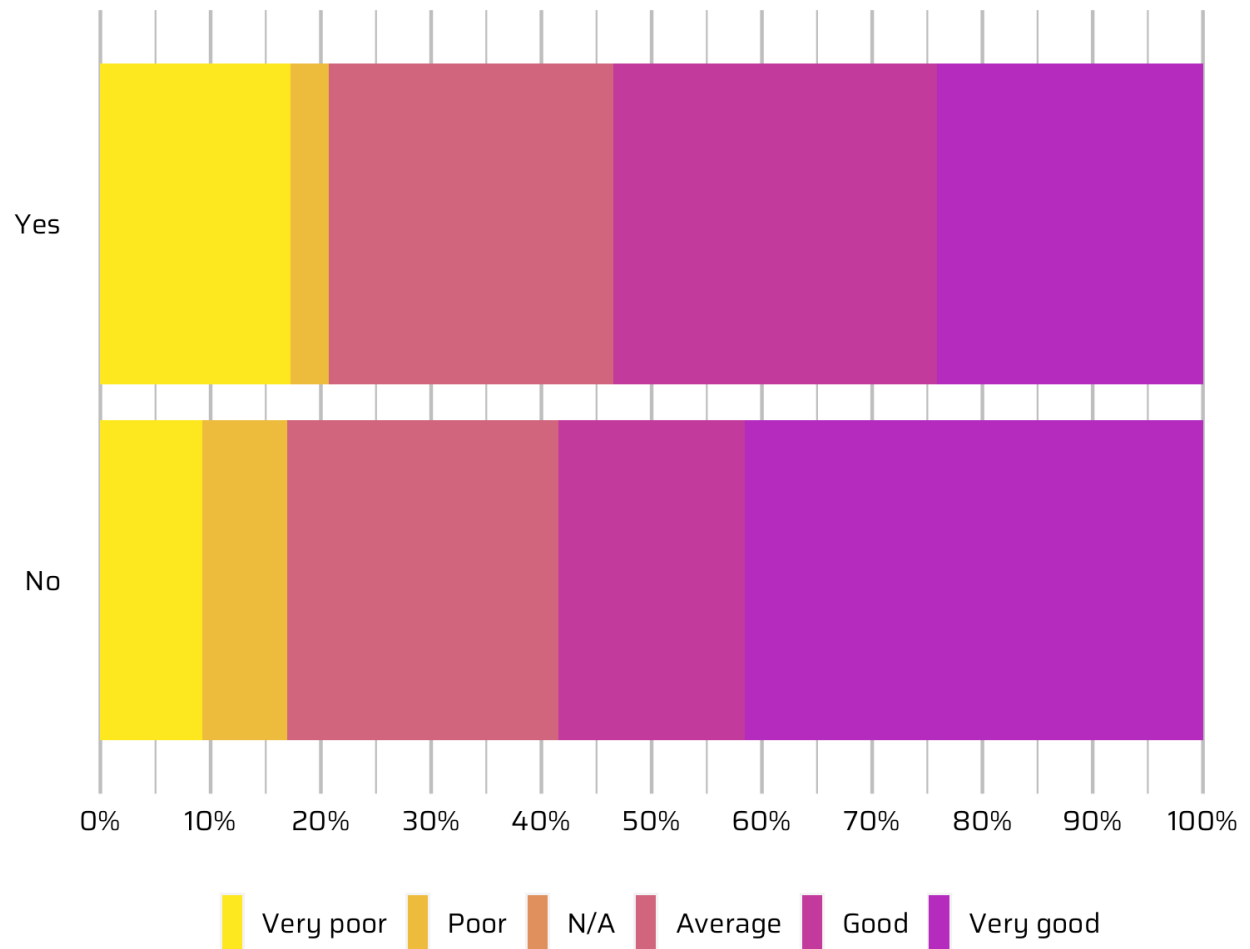


Table 15: No. of responses to the question 'Overall, what has your experience of care been like in the last 8 weeks?' by feelings of being anxious or hopeless

Anxious or Hopeless	Experience	Respondents	Percentage
Yes	Very good	14	24
Yes	Good	17	29
Yes	Average	15	26
Yes	N/A	0	0
Yes	Poor	2	3
Yes	Very poor	10	17
No	Very good	27	42
No	Good	11	17
No	Average	16	25
No	N/A	0	0
No	Poor	5	8
No	Very poor	6	9

Figure 16: Experience of care by delays to care

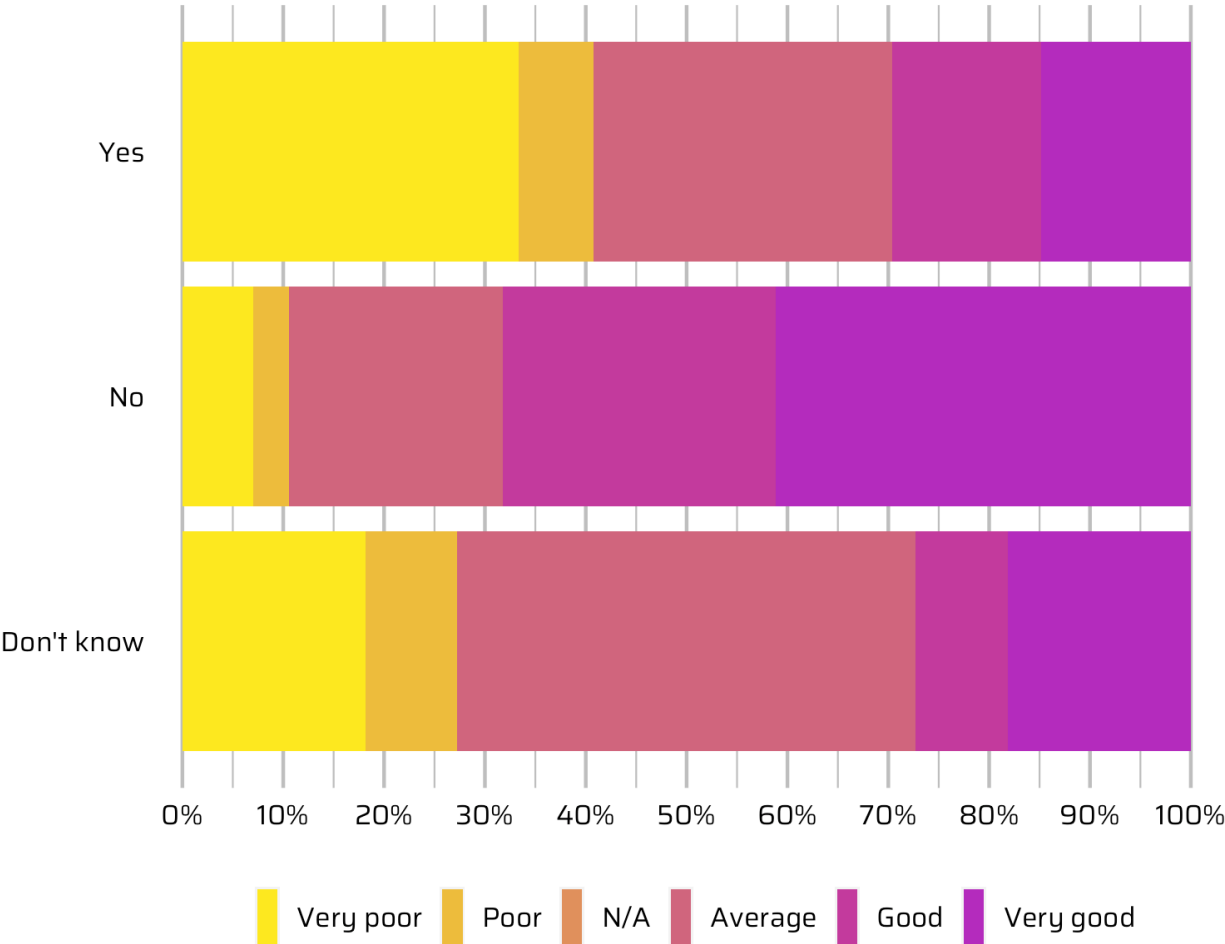


Table 16: No. of responses to the question 'Overall, what has your experience of care been like in the last 8 weeks?' by feelings of being anxious or hopeless

Delay	Experience	Respondents	Percentage
Yes	Very good	4	15
Yes	Good	4	15
Yes	Average	8	30
Yes	N/A	0	0
Yes	Poor	2	7
Yes	Very poor	9	33
No	Very good	35	41
No	Good	23	27
No	Average	18	21
No	N/A	0	0
No	Poor	3	4
No	Very poor	6	7
Don't know	Very good	2	18
Don't know	Good	1	9
Don't know	Average	5	45
Don't know	N/A	0	0
Don't know	Poor	1	9
Don't know	Very poor	2	18

Figure 17: Experience of care by cancellations to care

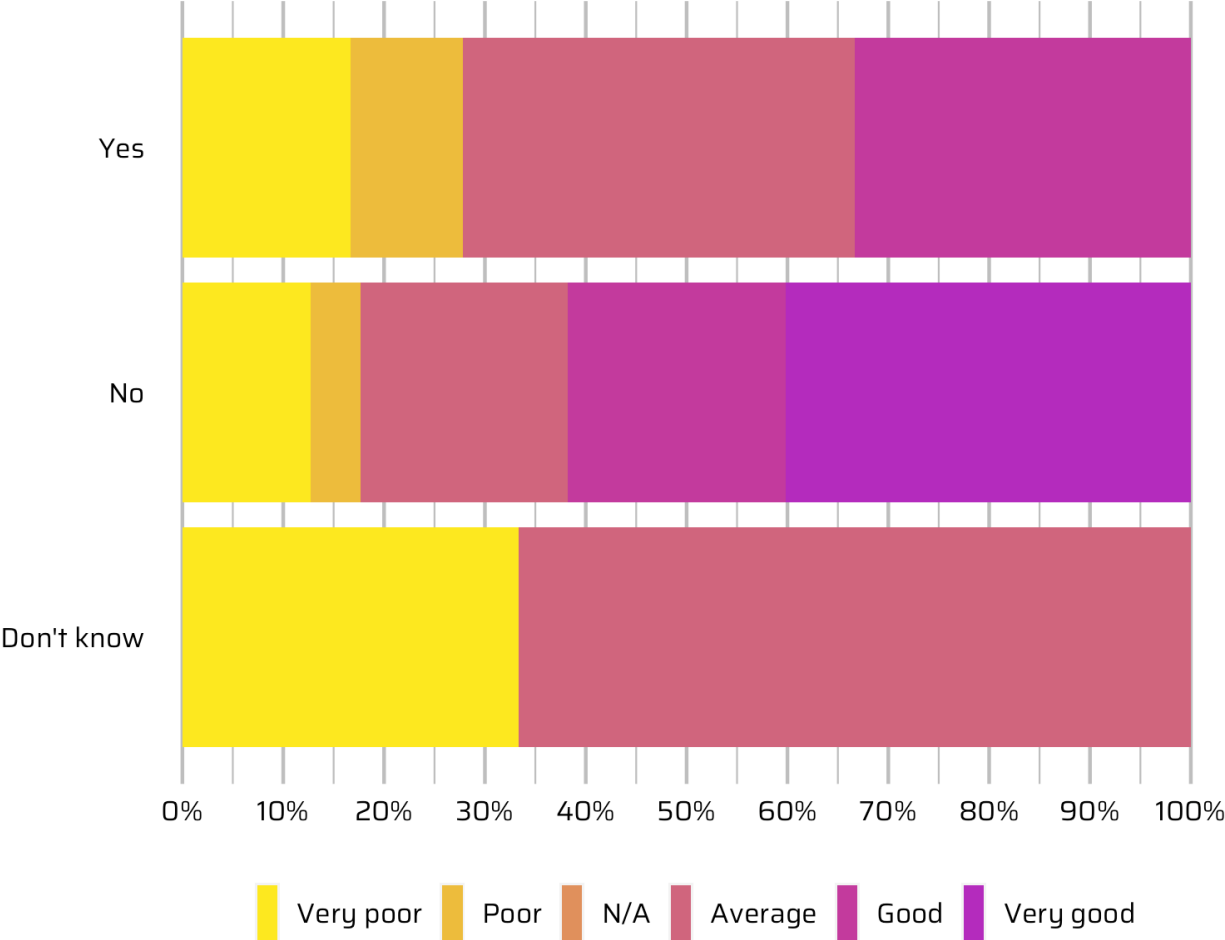


Table 17: No. of responses to the question 'Overall, what has your experience of care been like in the last 8 weeks?' by whether or not they had experienced cancellations of care

Cancellation	Experience	Respondents	Percentage
Yes	Very good	0	0
Yes	Good	6	33
Yes	Average	7	39
Yes	N/A	0	0
Yes	Poor	2	11
Yes	Very poor	3	17
No	Very good	41	40
No	Good	22	22
No	Average	21	21
No	N/A	0	0
No	Poor	5	5
No	Very poor	13	13
Don't know	Very good	0	0
Don't know	Good	0	0
Don't know	Average	2	67
Don't know	N/A	0	0
Don't know	Poor	0	0
Don't know	Very poor	1	33

Figure 18: Experience of care by financial status

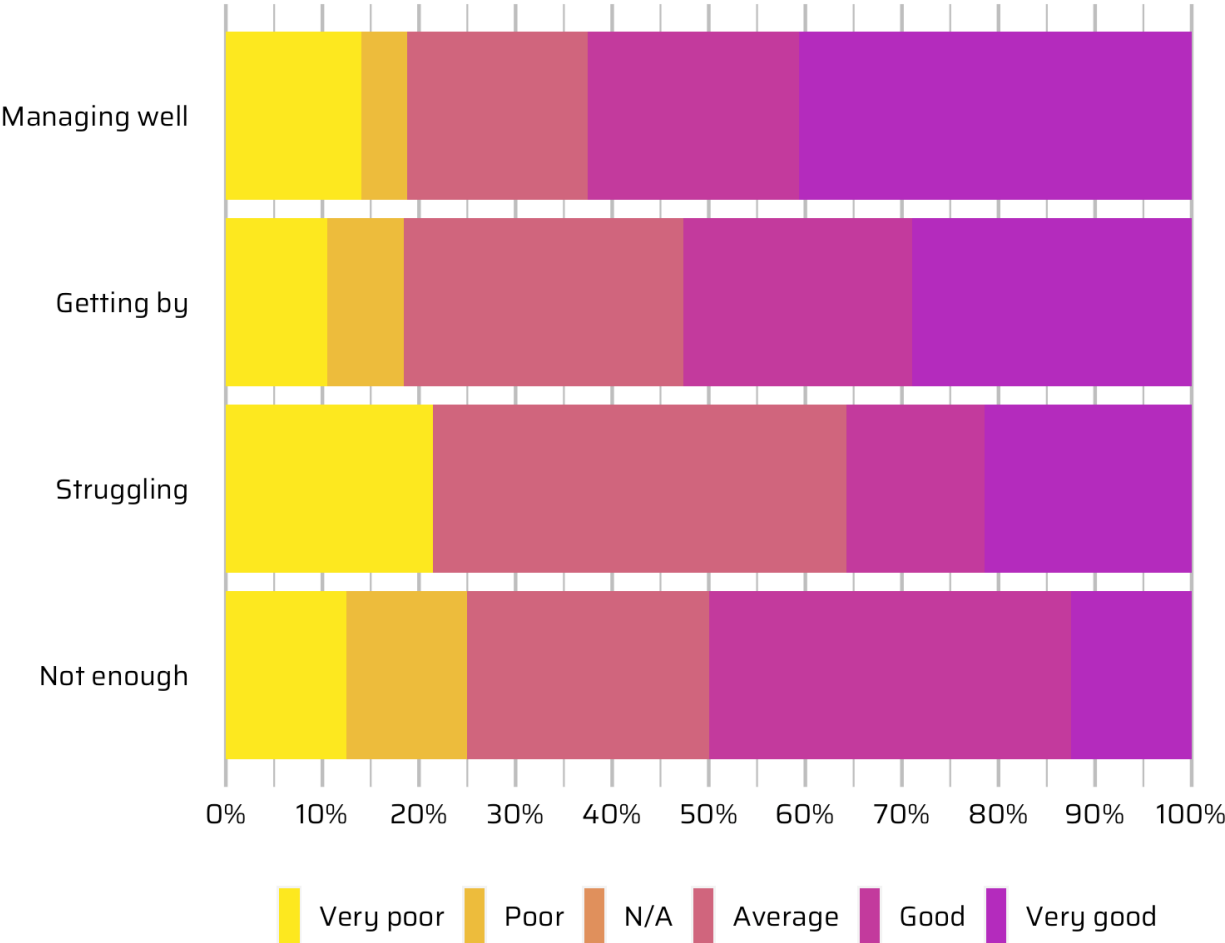


Table 18: No. of responses to the question 'Overall, what has your experience of care been like in the last 8 weeks?' by reported financial status

Financial Status	Experience	Respondents	Percentage
Managing well	Very good	26	41
Managing well	Good	14	22
Managing well	Average	12	19
Managing well	N/A	0	0
Managing well	Poor	3	5
Managing well	Very poor	9	14
Getting by	Very good	11	29
Getting by	Good	9	24
Getting by	Average	11	29
Getting by	N/A	0	0
Getting by	Poor	3	8
Getting by	Very poor	4	11
Struggling	Very good	3	21
Struggling	Good	2	14
Struggling	Average	6	43
Struggling	N/A	0	0
Struggling	Poor	0	0
Struggling	Very poor	3	21
Not enough	Very good	1	12
Not enough	Good	3	38
Not enough	Average	2	25
Not enough	N/A	0	0
Not enough	Poor	1	12
Not enough	Very poor	1	12

Figure 19: Experience of care by age group

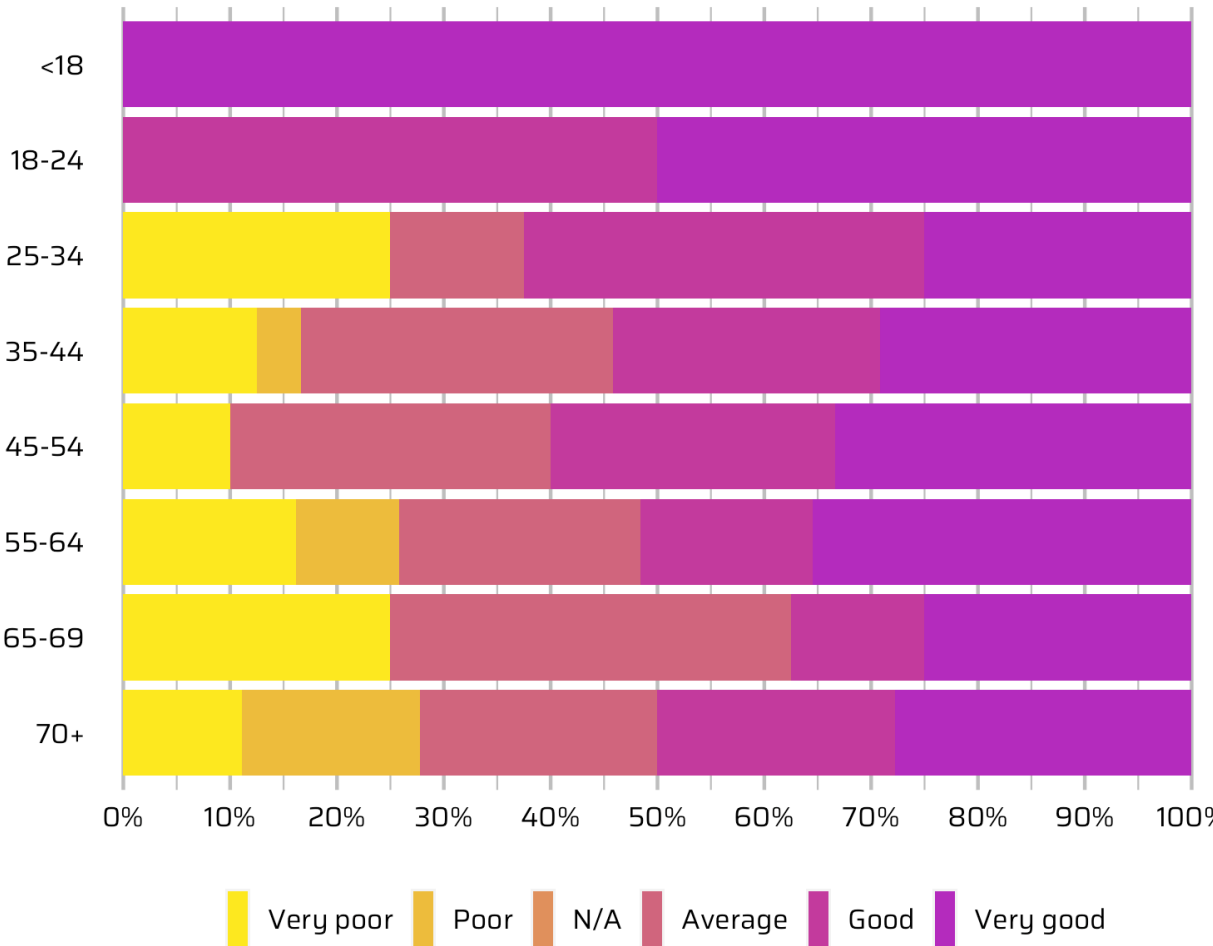


Table 19: No. of responses to the question 'Overall, what has your experience of care been like in the last 8 weeks?' by age group

Age	Experience	Respondents	Percentage
<18	Very good	3	100
<18	Good	0	0
<18	Average	0	0
<18	N/A	0	0
<18	Poor	0	0
<18	Very poor	0	0
18-24	Very good	1	50
18-24	Good	1	50
18-24	Average	0	0
18-24	N/A	0	0
18-24	Poor	0	0
18-24	Very poor	0	0
25-34	Very good	2	25
25-34	Good	3	38
25-34	Average	1	12
25-34	N/A	0	0
25-34	Poor	0	0
25-34	Very poor	2	25
35-44	Very good	7	29
35-44	Good	6	25
35-44	Average	7	29
35-44	N/A	0	0
35-44	Poor	1	4
35-44	Very poor	3	12
45-54	Very good	10	33
45-54	Good	8	27
45-54	Average	9	30
45-54	N/A	0	0
45-54	Poor	0	0
45-54	Very poor	3	10
55-64	Very good	11	35
55-64	Good	5	16
55-64	Average	7	23
55-64	N/A	0	0
55-64	Poor	3	10

55-64	Very poor	5	16
65-69	Very good	2	25
65-69	Good	1	12
65-69	Average	3	38
65-69	N/A	0	0
65-69	Poor	0	0
65-69	Very poor	2	25
70+	Very good	5	28
70+	Good	4	22
70+	Average	4	22
70+	N/A	0	0
70+	Poor	3	17
70+	Very poor	2	11

Figure 20: Delays to care by feelings of anxiety or hopelessness

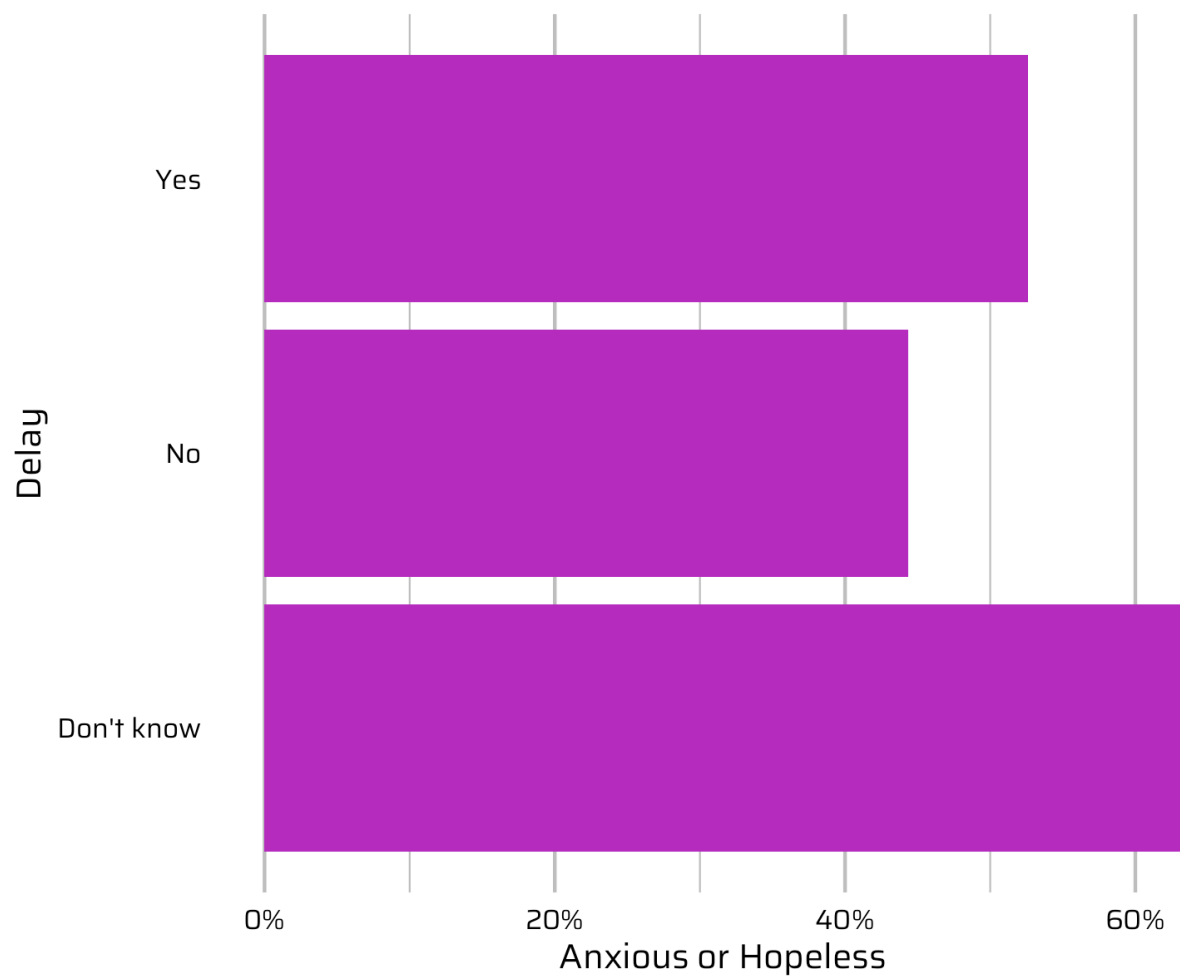


Table 20: No. and type of responses to the question 'Did you experience delays to your care?' by feelings of anxiety or hopelessness

Delay	Anxious or Hopeless	Respondents	Percentage
Yes	Yes	20	53
Yes	No	18	47
No	Yes	63	44
No	No	79	56
Don't know	Yes	12	63
Don't know	No	7	37

Figure 21: Cancellations to care by feelings of anxiety or hopelessness

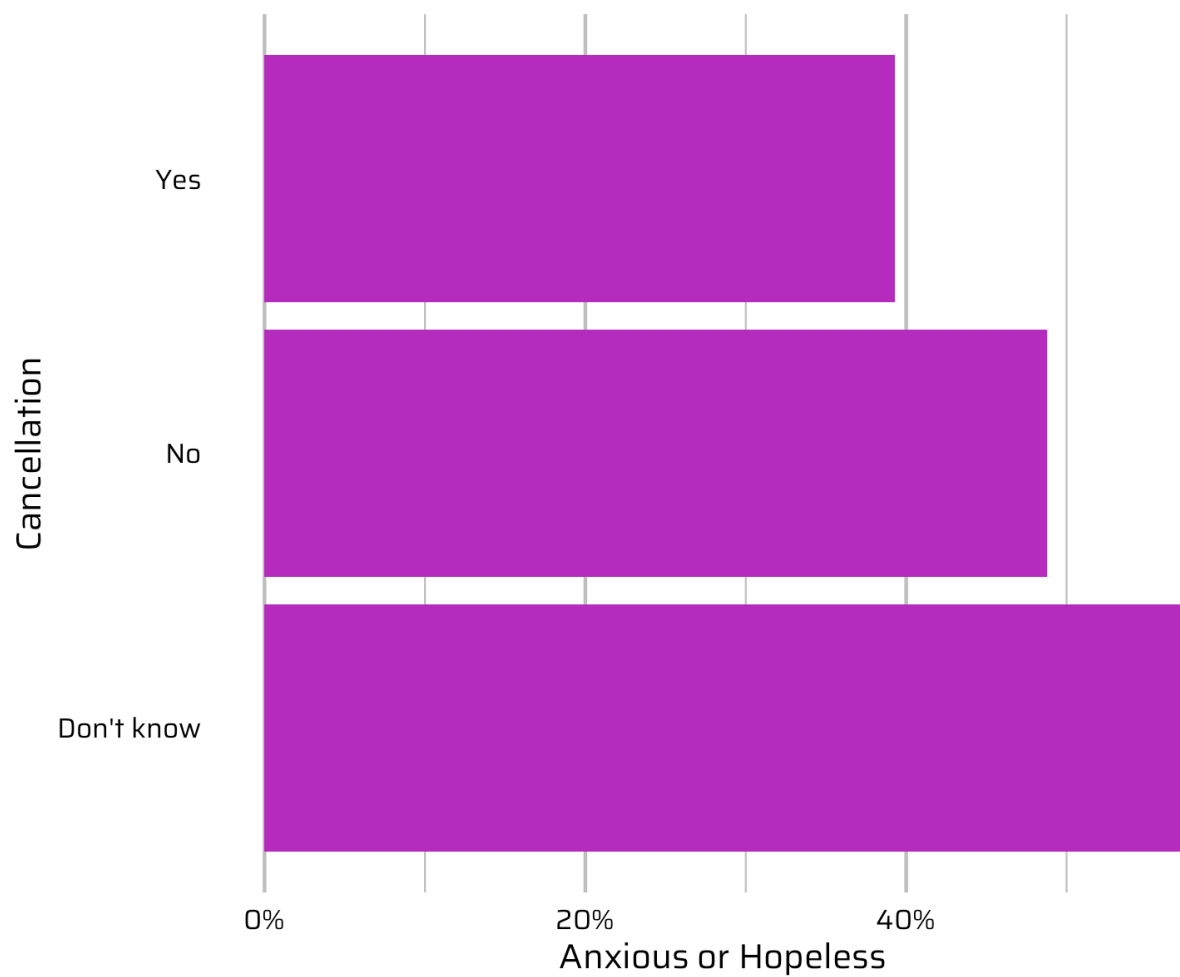


Table 21: No. and type of responses to the question 'Did you experience cancellations to your care?' by feelings of anxiety or hopelessness

Cancellation	Anxious or Hopeless	Respondents	Percentage
Yes	Yes	11	39
Yes	No	17	61
No	Yes	80	49
No	No	84	51
Don't know	Yes	4	57
Don't know	No	3	43

Emergency Support

Figure 22: How many times have you sought emergency care in the last 4 weeks?

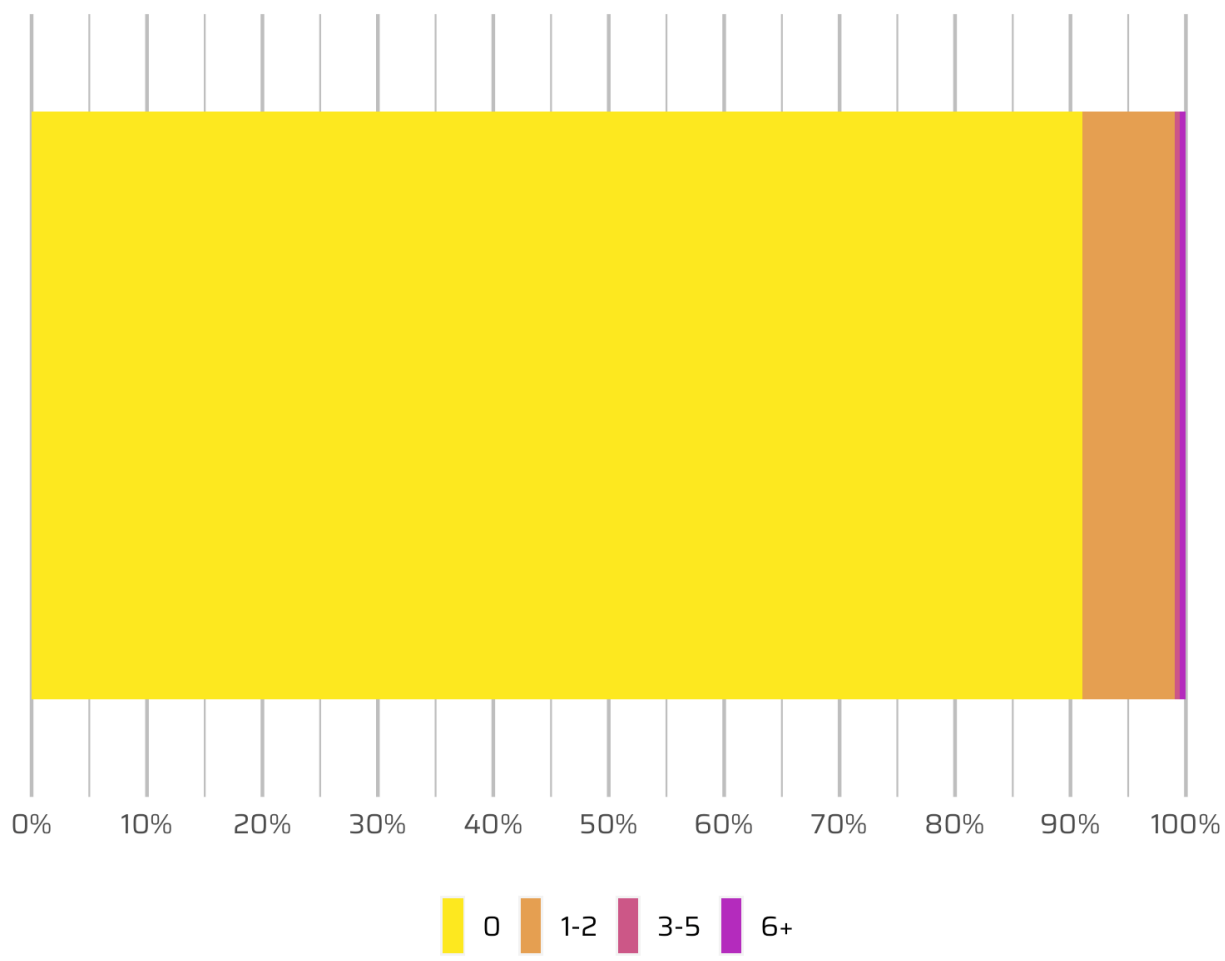


Table 22: No. of responses to the question 'How many times have you sought emergency support in the past 4 weeks?'

Frequency	Respondents	Percentage
6+	1	0
3-5	1	0
1-2	16	8
0	182	91

Figure 23: Emergency support by gender

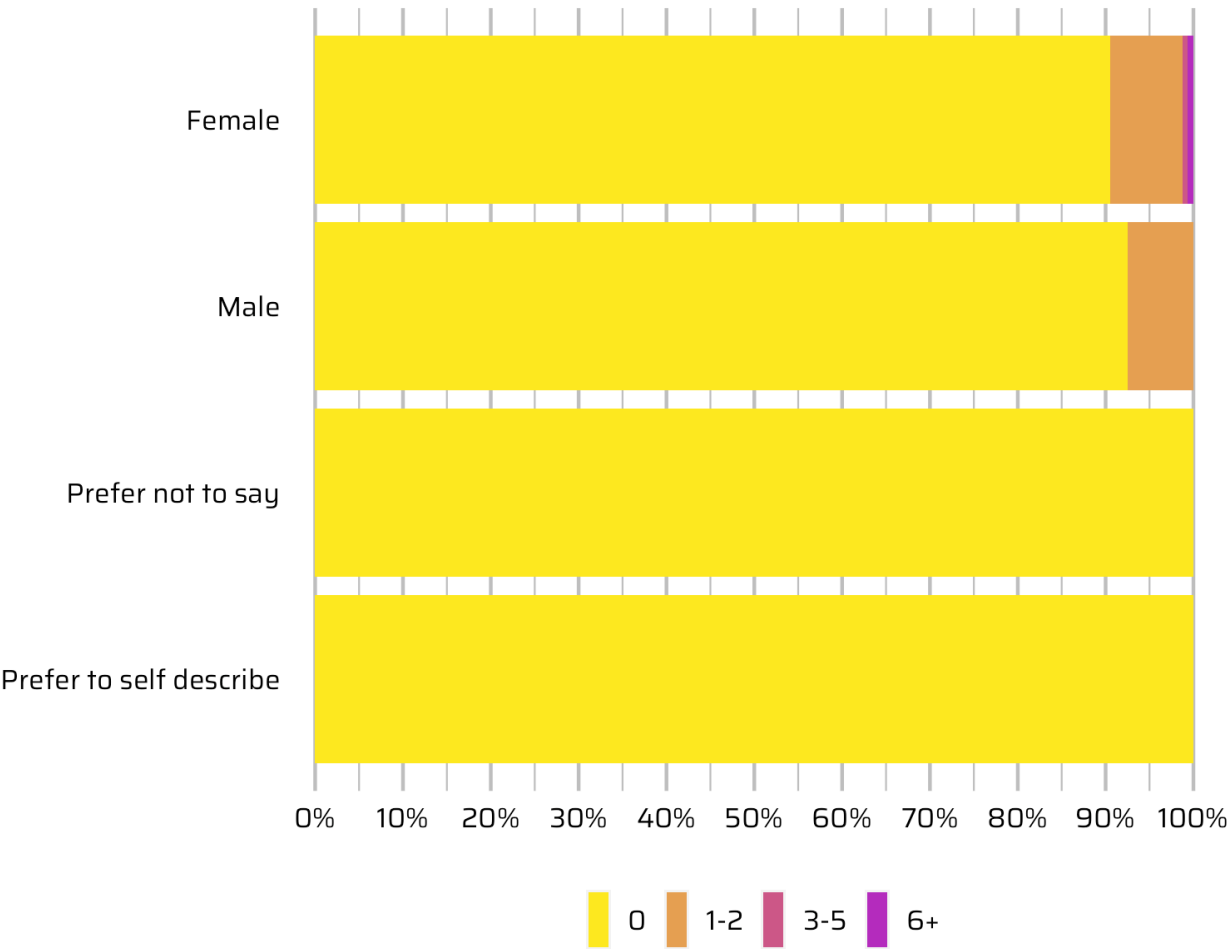


Table 23: No. of responses to the question 'How many times have you sought emergency support in the past 4 weeks?' by gender

Gender	Frequency	Respondents	Percentage
Female	6+	1	1
Female	3-5	1	1
Female	1-2	13	8
Female	0	143	91
Male	6+	0	0
Male	3-5	0	0
Male	1-2	3	8
Male	0	37	92
Prefer not to say	6+	0	0
Prefer not to say	3-5	0	0
Prefer not to say	1-2	0	0
Prefer not to say	0	1	100
Prefer to self describe	6+	0	0
Prefer to self describe	3-5	0	0
Prefer to self describe	1-2	0	0
Prefer to self describe	0	1	100

Figure 24: Emergency support by employment status

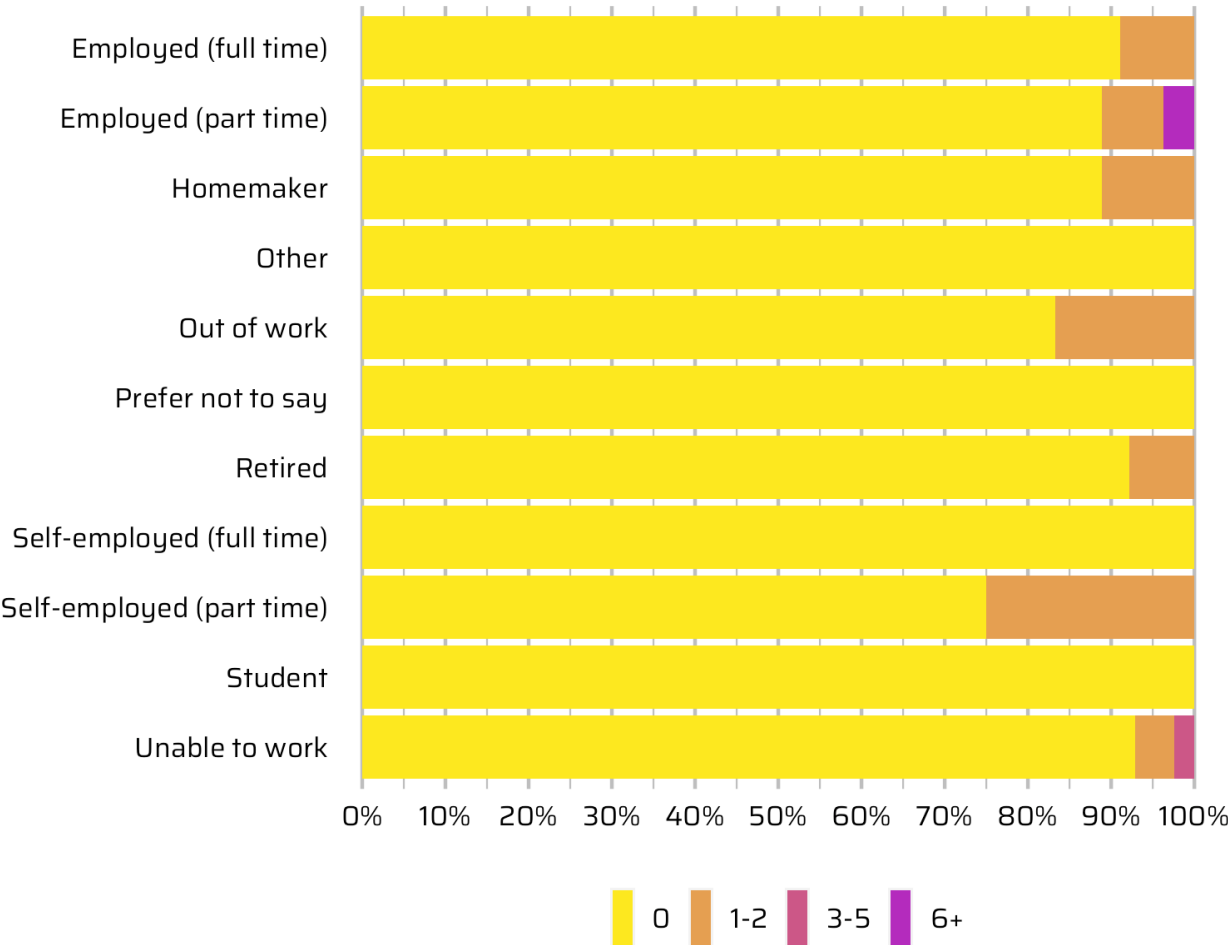


Table 24: No. of responses to the question 'How many times have you sought emergency support in the past 4 weeks?' by employment status

Employment Status	Frequency	Respondents	Percentage
Employed (full time)	6+	0	0
Employed (full time)	3-5	0	0
Employed (full time)	1-2	4	9
Employed (full time)	0	41	91
Employed (part time)	6+	1	4
Employed (part time)	3-5	0	0
Employed (part time)	1-2	2	7
Employed (part time)	0	24	89
Homemaker	6+	0	0
Homemaker	3-5	0	0
Homemaker	1-2	1	11
Homemaker	0	8	89
Other	6+	0	0
Other	3-5	0	0
Other	1-2	0	0
Other	0	6	100
Out of work	6+	0	0
Out of work	3-5	0	0
Out of work	1-2	1	17
Out of work	0	5	83
Prefer not to say	6+	0	0
Prefer not to say	3-5	0	0
Prefer not to say	1-2	0	0
Prefer not to say	0	3	100
Retired	6+	0	0
Retired	3-5	0	0
Retired	1-2	4	8
Retired	0	47	92
Self-employed (full time)	6+	0	0
Self-employed (full time)	3-5	0	0
Self-employed (full time)	1-2	0	0
Self-employed (full time)	0	3	100
Self-employed (part time)	6+	0	0
Self-employed (part time)	3-5	0	0
Self-employed (part time)	1-2	1	25

Self-employed (part time)	0	3	75
Student	6+	0	0
Student	3-5	0	0
Student	1-2	0	0
Student	0	1	100
Unable to work	6+	0	0
Unable to work	3-5	1	2
Unable to work	1-2	2	5
Unable to work	0	39	93

Figure 25: Emergency support by number of dependents

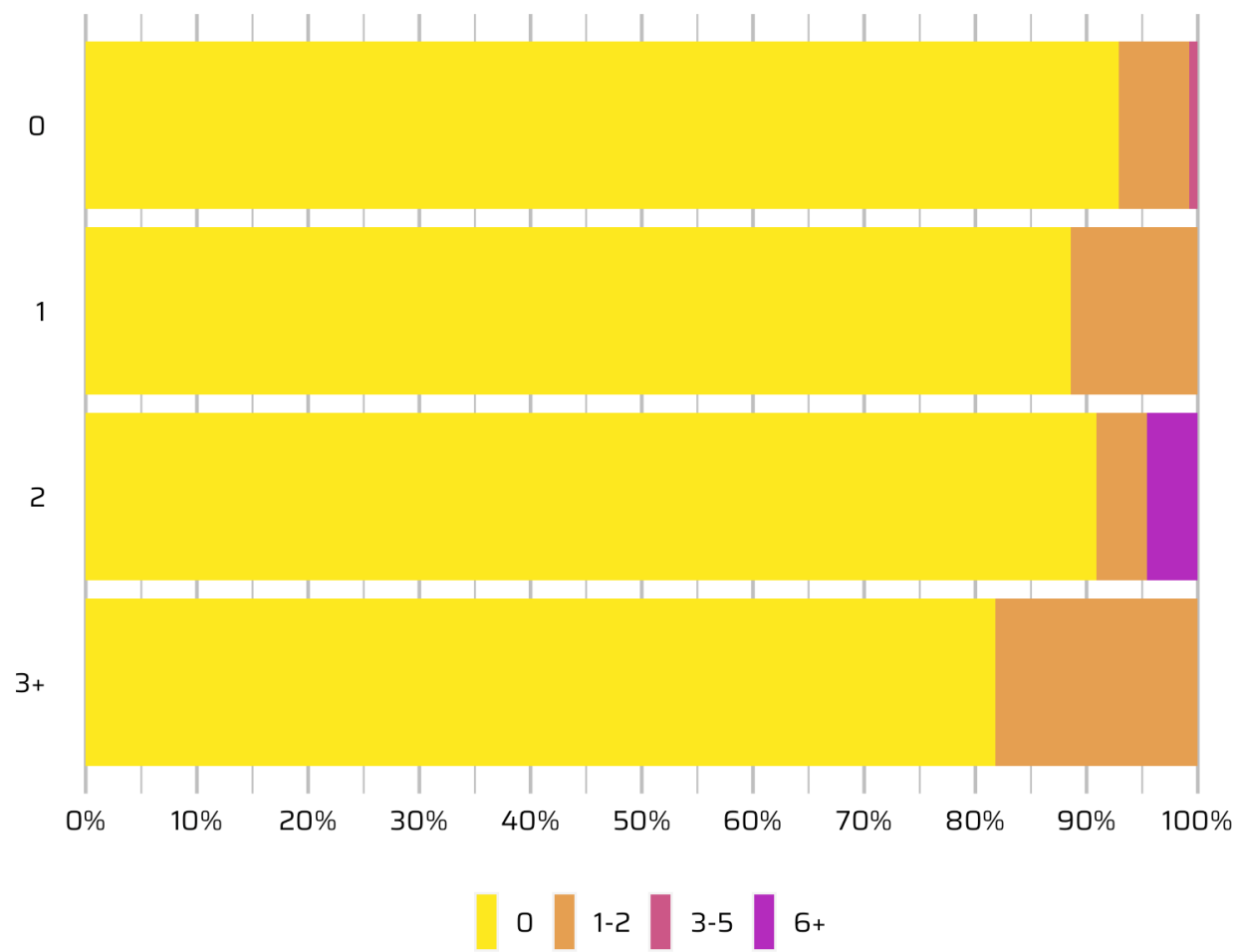


Table 25: No. of responses to the question 'How many times have you sought emergency support in the past 4 weeks?' by number of dependents

Dependents	Frequency	Respondents	Percentage
0	6+	0	0
0	3-5	1	1
0	1-2	8	6
0	0	118	93
1	6+	0	0
1	3-5	0	0
1	1-2	4	11
1	0	31	89
2	6+	1	5
2	3-5	0	0
2	1-2	1	5
2	0	20	91
3+	6+	0	0
3+	3-5	0	0
3+	1-2	2	18
3+	0	9	82

Figure 26: Marital status by frequency of emergency support

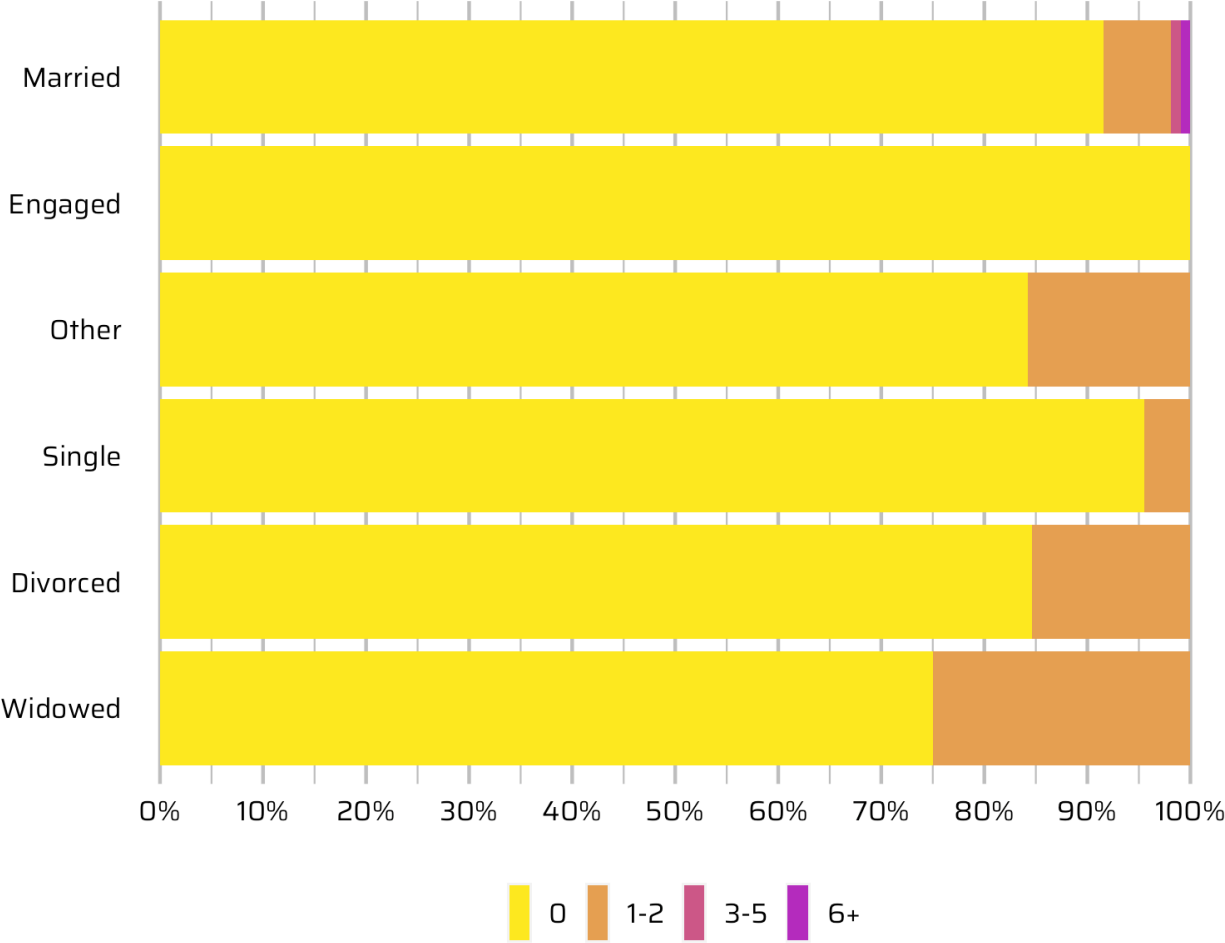


Table 26: No. of responses to the question 'How many times have you sought emergency support in the past 4 weeks?' by number of marital status

Marital Status	Frequency	Respondents	Percentage
Married	6+	1	1
Married	3-5	1	1
Married	1-2	7	7
Married	0	98	92
Engaged	6+	0	0
Engaged	3-5	0	0
Engaged	1-2	0	0
Engaged	0	6	100
Other	6+	0	0
Other	3-5	0	0
Other	1-2	3	16
Other	0	16	84
Single	6+	0	0
Single	3-5	0	0
Single	1-2	2	4
Single	0	43	96
Divorced	6+	0	0
Divorced	3-5	0	0
Divorced	1-2	2	15
Divorced	0	11	85
Widowed	6+	0	0
Widowed	3-5	0	0
Widowed	1-2	2	25
Widowed	0	6	75

Figure 27: Anxious or Hopeless Feeling and frequency of emergency support

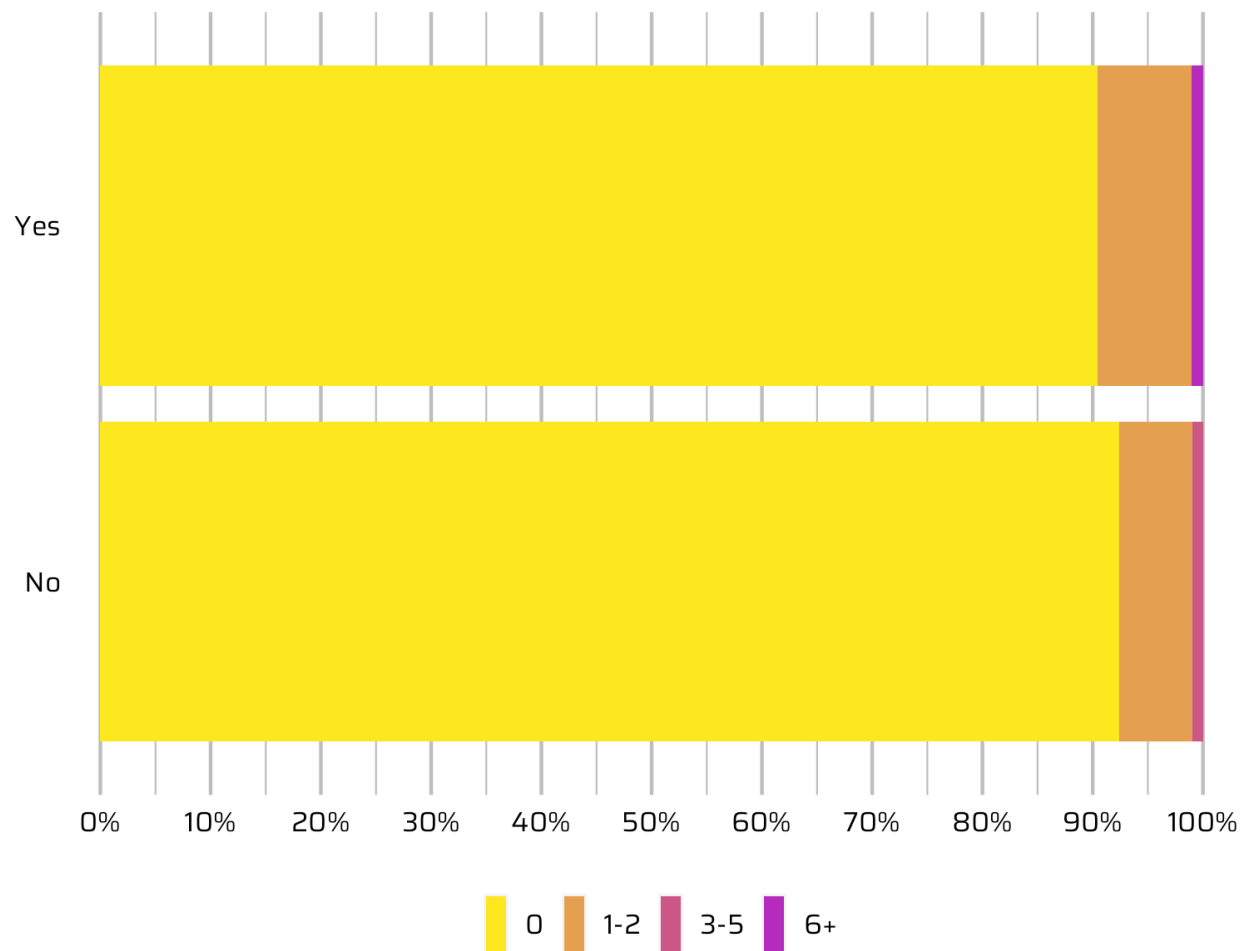


Table 27: No. of responses to the question 'How many times have you sought emergency support in the past 8 weeks?' by those who reported feelings of anxiety and/or hopelessness

Anxious or Hopeless	Frequency	Respondents	Percentage
Yes	6+	1	1
Yes	3-5	0	0
Yes	1-2	8	9
Yes	0	85	90
No	6+	0	0
No	3-5	1	1
No	1-2	7	7
No	0	97	92

Figure 28: Delays to Care and frequency of emergency support

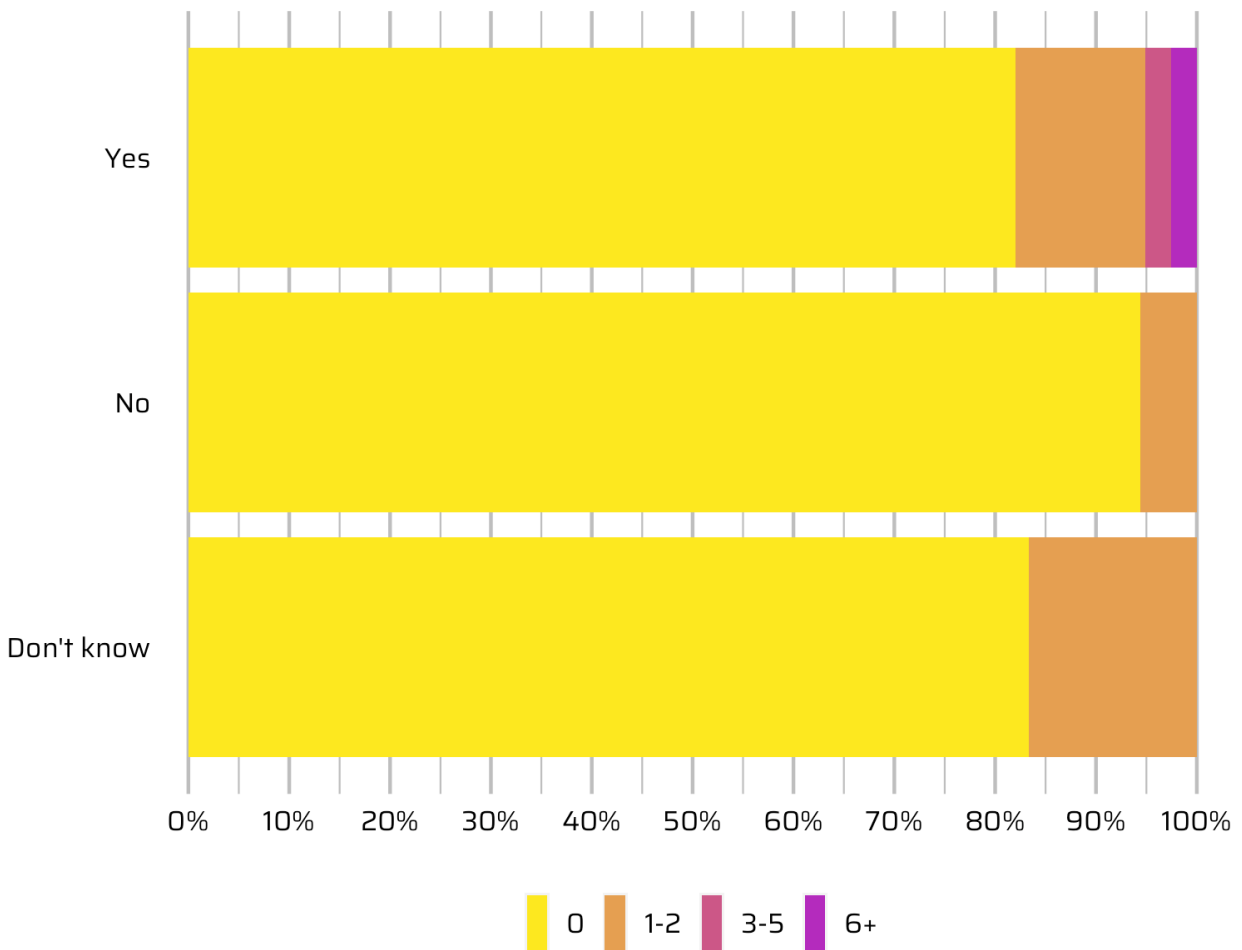


Table 28: No. of responses to the question 'How many times have you sought emergency support in the past 8 weeks?' by those who reported delays to care

Delay	Frequency	Respondents	Percentage
Yes	6+	1	3
Yes	3-5	1	3
Yes	1-2	5	13
Yes	0	32	82
No	6+	0	0
No	3-5	0	0
No	1-2	8	6
No	0	134	94
Don't know	6+	0	0
Don't know	3-5	0	0
Don't know	1-2	3	17
Don't know	0	15	83

Figure 29: Cancellation of Care and frequency of emergency support

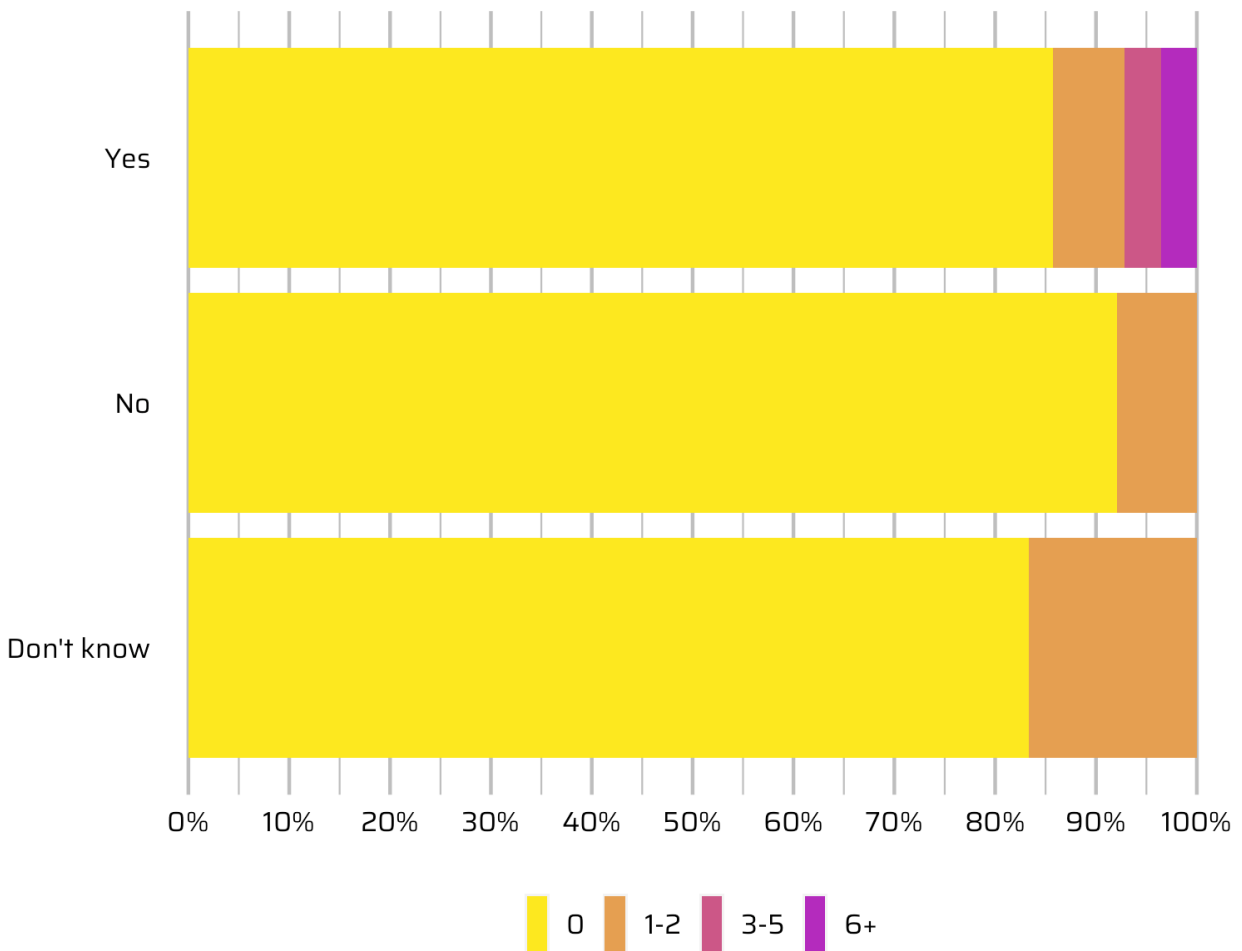


Table 29: No. of responses to the question 'How many times have you sought emergency support in the past 4 weeks?' by those who reported cancellations to care

Cancellation	Frequency	Respondents	Percentage
Yes	6+	1	4
Yes	3-5	1	4
Yes	1-2	2	7
Yes	0	24	86
No	6+	0	0
No	3-5	0	0
No	1-2	13	8
No	0	152	92
Don't know	6+	0	0
Don't know	3-5	0	0

Don't know	1-2	1	17
Don't know	0	5	83

Figure 30: Financial Status and frequency of emergency support

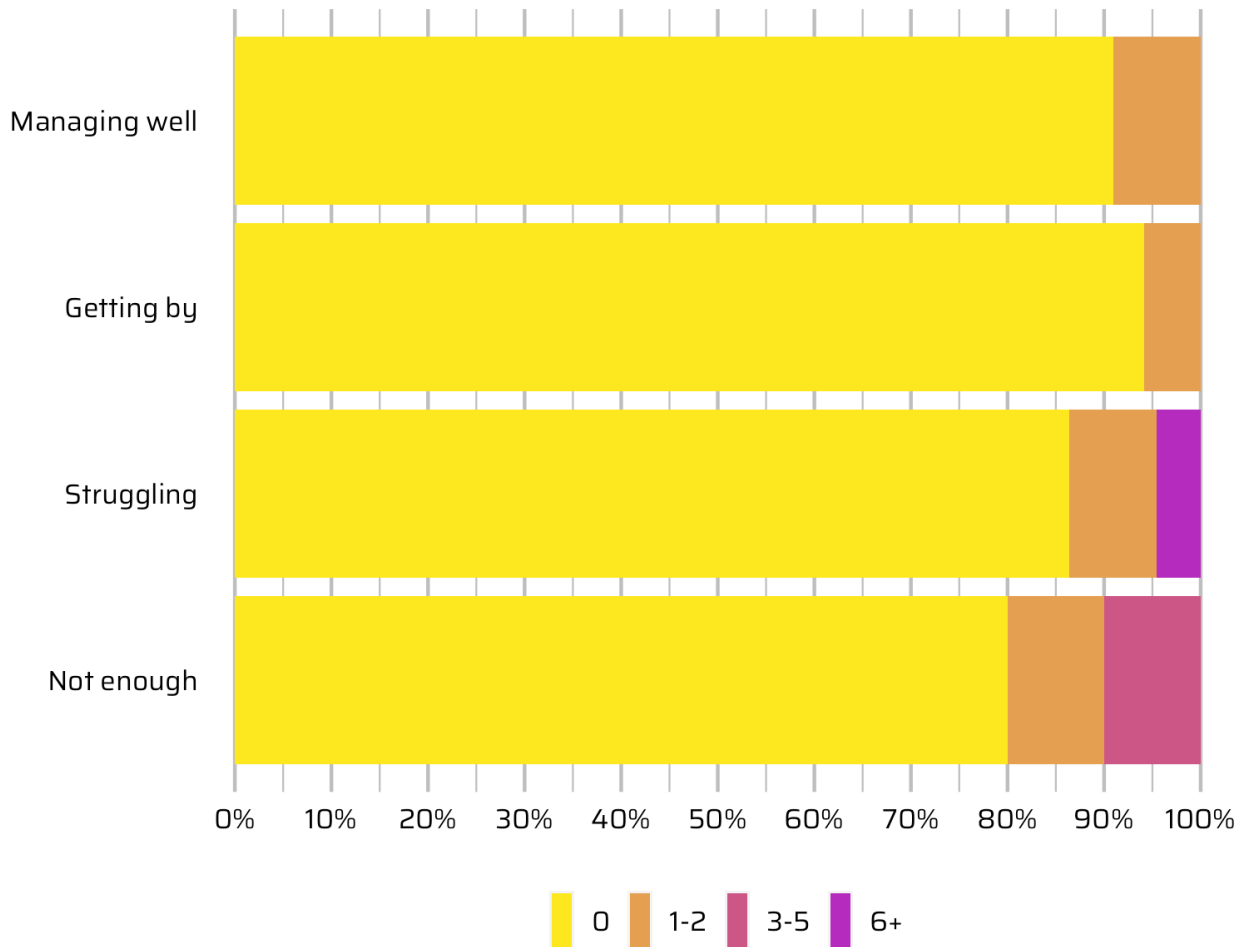


Table 30: No. of responses to the question 'How many times have you sought emergency support in the past 4 weeks?' by financial status

Financial Status	Frequency	Respondents	Percentage
Managing well	6+	0	0
Managing well	3-5	0	0
Managing well	1-2	9	9
Managing well	0	91	91
Getting by	6+	0	0
Getting by	3-5	0	0
Getting by	1-2	4	6
Getting by	0	64	94
Struggling	6+	1	5
Struggling	3-5	0	0
Struggling	1-2	2	9
Struggling	0	19	86
Not enough	6+	0	0
Not enough	3-5	1	10
Not enough	1-2	1	10
Not enough	0	8	80

Figure 31: Age and frequency of emergency support

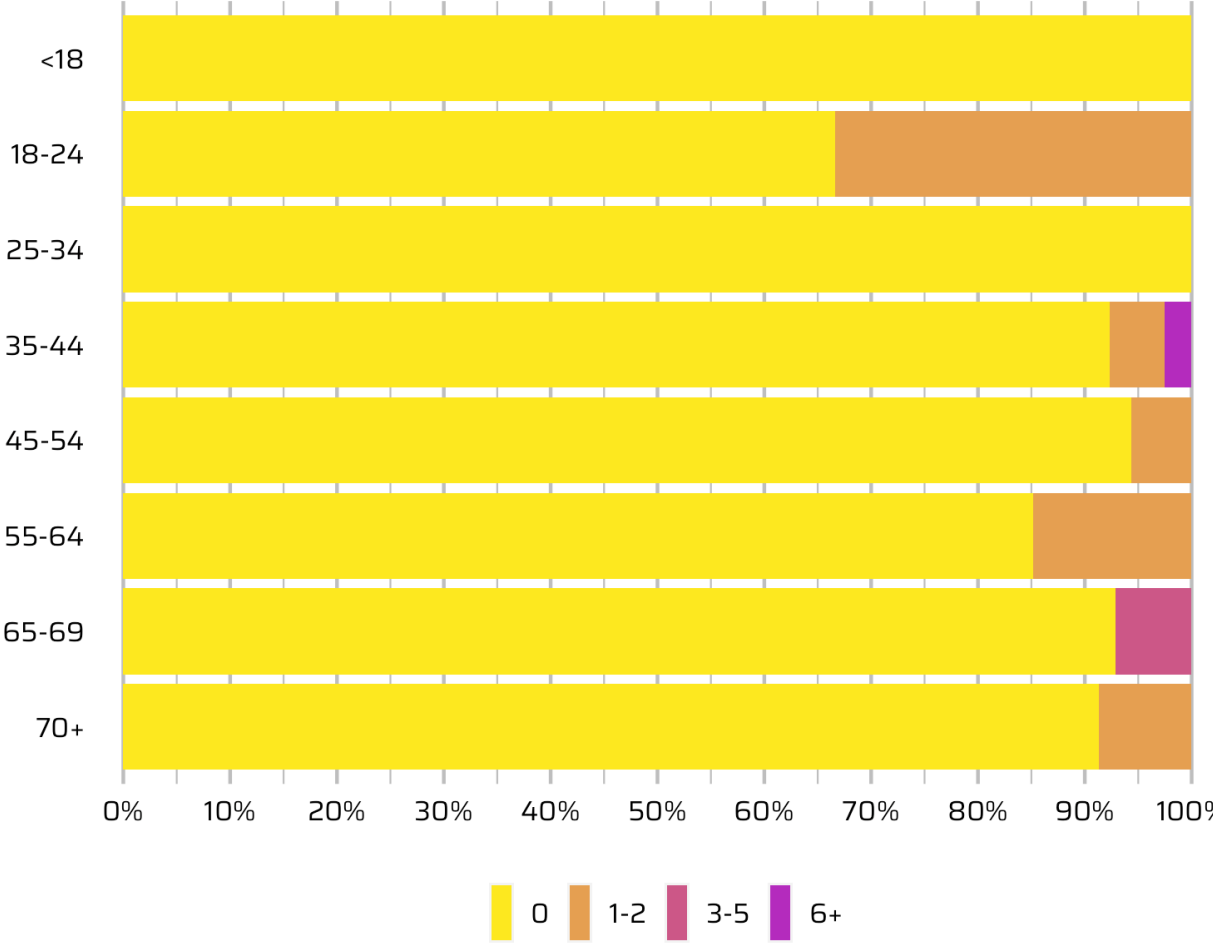


Table 31: No. of responses to the question 'How many times have you sought emergency support in the past 8 weeks?' by age group

Age	Frequency	Respondents	Percentage
<18	6+	0	0
<18	3-5	0	0
<18	1-2	0	0
<18	0	3	100
18-24	6+	0	0
18-24	3-5	0	0
18-24	1-2	1	33
18-24	0	2	67
25-34	6+	0	0
25-34	3-5	0	0
25-34	1-2	0	0
25-34	0	11	100
35-44	6+	1	3
35-44	3-5	0	0
35-44	1-2	2	5
35-44	0	36	92
45-54	6+	0	0
45-54	3-5	0	0
45-54	1-2	3	6
45-54	0	50	94
55-64	6+	0	0
55-64	3-5	0	0
55-64	1-2	8	15
55-64	0	46	85
65-69	6+	0	0
65-69	3-5	1	7
65-69	1-2	0	0
65-69	0	13	93
70+	6+	0	0
70+	3-5	0	0
70+	1-2	2	9
70+	0	21	91

Figure 32: Change to emergency support

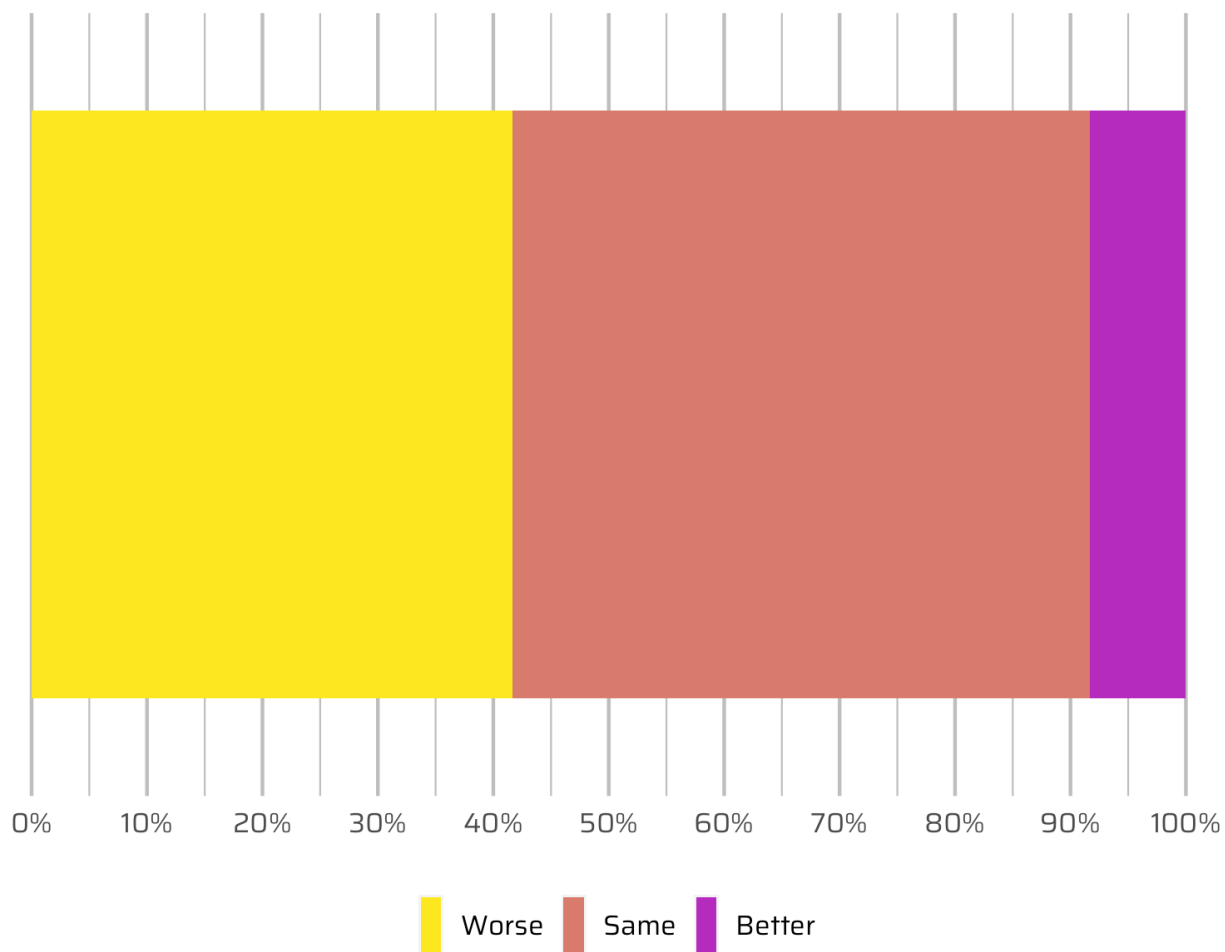


Table 32: No. of responses to the question 'Overall, do you feel that your experience of emergency care was different during the COVID-19 pandemic compared to before the pandemic?'

Change	Respondents	Percentage
Better	1	8
Same	6	50
Worse	5	42

Access to planned care

Figure 33: Proportion of respondents who had accessed support in the past 8 weeks

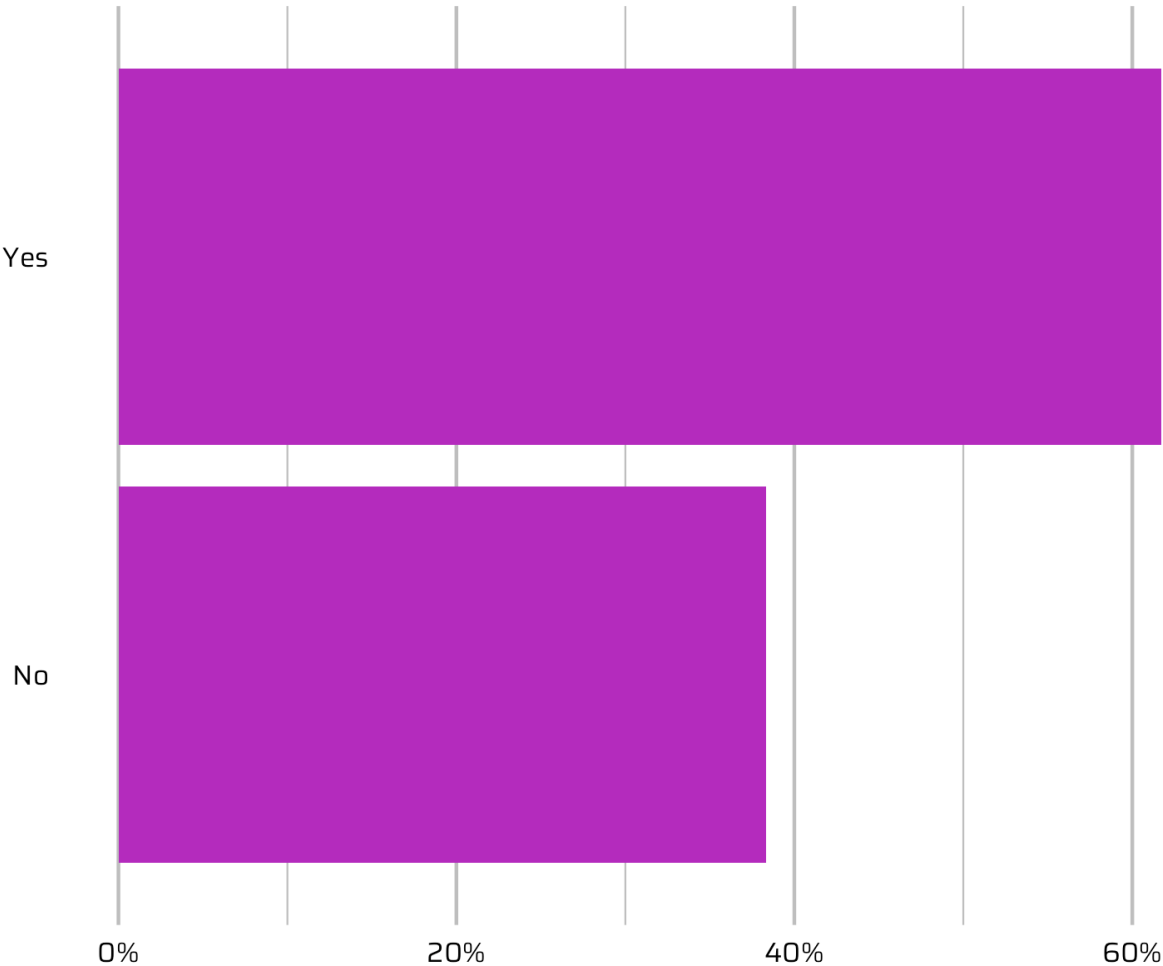


Table 33: No. of responses to the question 'Have you accessed treatment, care or support for your neurological condition in the past 8 weeks?'

Access	Respondents	Percentage
Yes	124	62
No	77	38

Figure 34: Number of Medical Appointments in the past 8 weeks

Nota bene: The basis for the percentages in this section is the number of observations as opposed to the number of respondents. A single respondent may have had multiple medical appointments and thus multiple observations.

Nota bene: Some respondents indicated they had had no treatment, care or support but also indicated they had accessed medical appointments in the past 8 weeks. This may have been as a result of incorrect questionnaire flow, which we are investigating further. For completeness, we have included all responses provided.

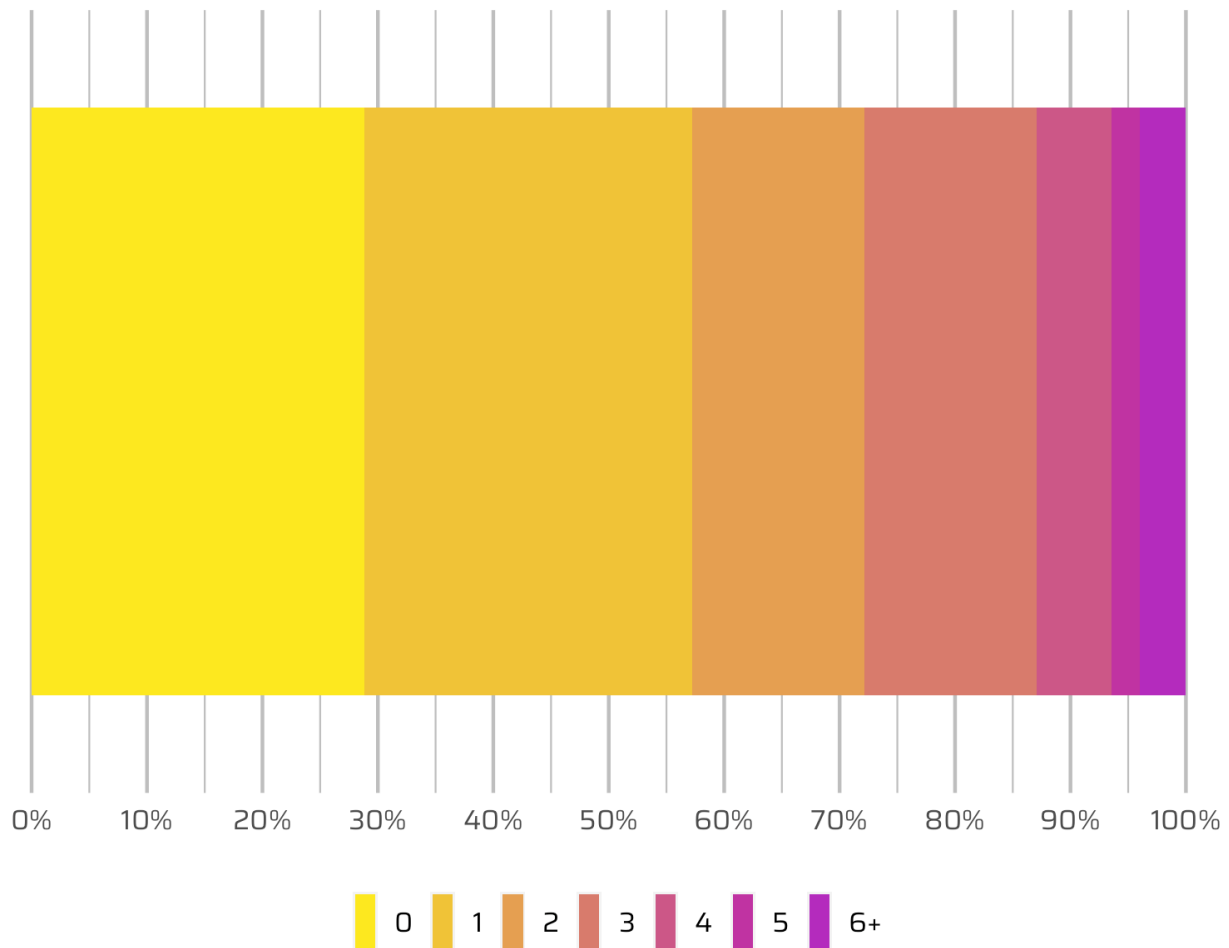


Table 34: No. of responses to the question 'How many medical appointments (including remote appointments) have you had in the last 8 weeks?

Number	Respondents	Percentage
6+	8	4
5	5	2
4	13	6
3	30	15
2	30	15
1	57	28
0	58	29

Figure 35: Helpfulness of medical appointments

Nota bene: The basis for the percentages in this section is the number of observations as opposed to the number of respondents. A single respondent may have had multiple medical appointments and thus multiple observations.

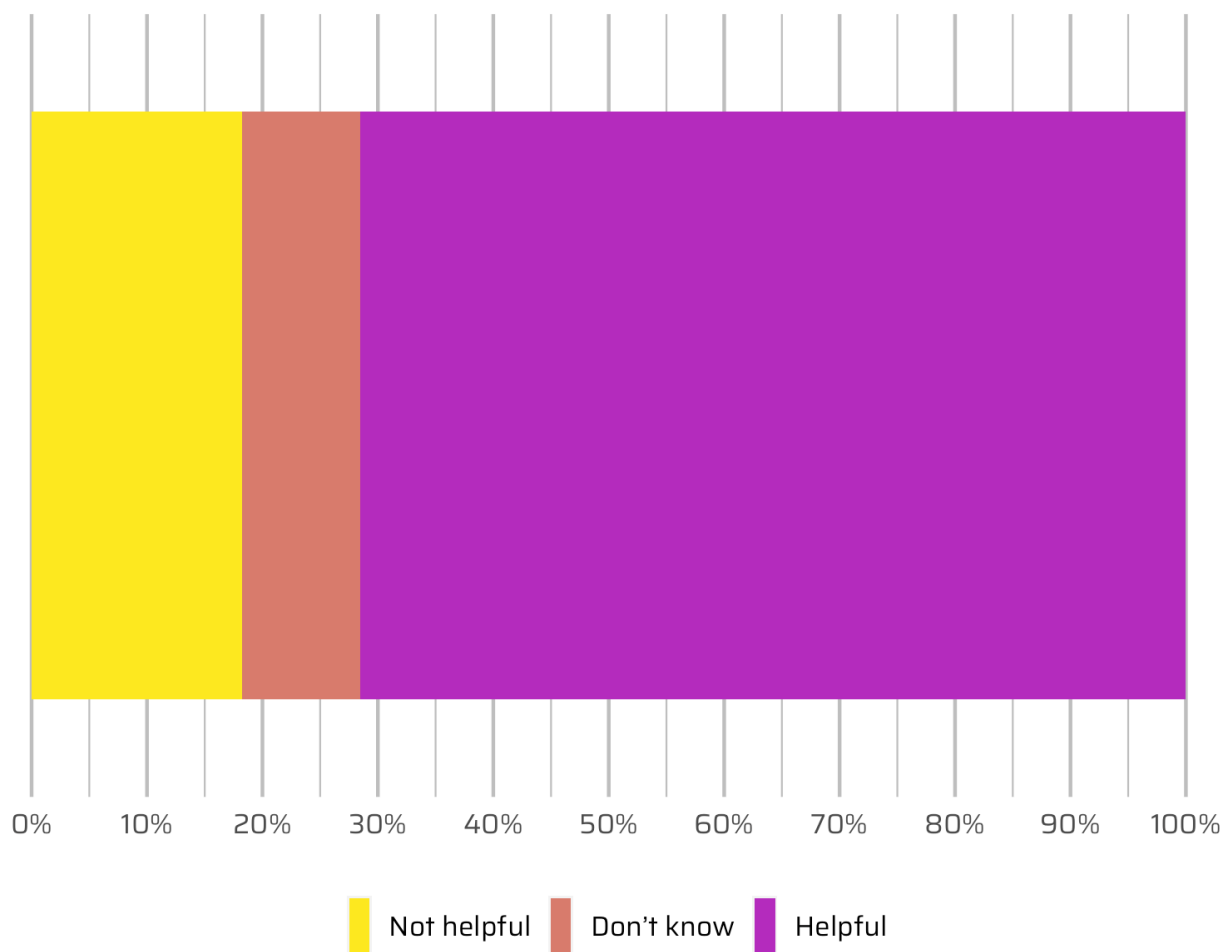


Table 35: Helpfulness of medical appointments

Helpfulness	Observations	Percentage
Helpful	224	72
Don't know	32	10
Not helpful	57	18

Figure 36: Type of appointment

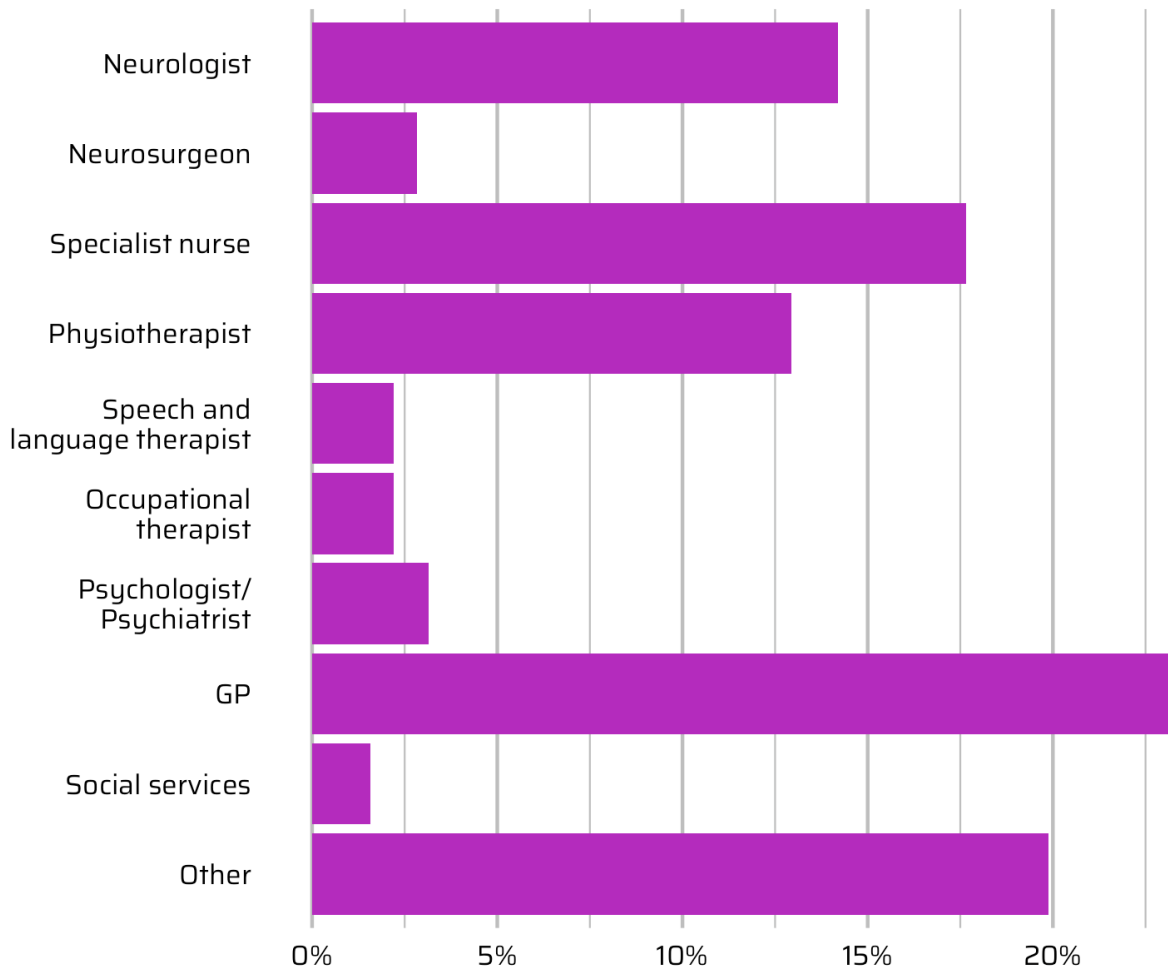


Table 36: Type of medical appointment

Specialty	Observations	Percentage
Neurologist	45	14
Neurosurgeon	9	3
Specialist nurse	56	18
Physiotherapist	41	13
Speech and language therapist	7	2
Occupational therapist	7	2
Psychologist/Psychiatrist	10	3
GP	74	23
Social services	5	2
Other	63	20

Figure 37: Helpfulness of appointment by specialty

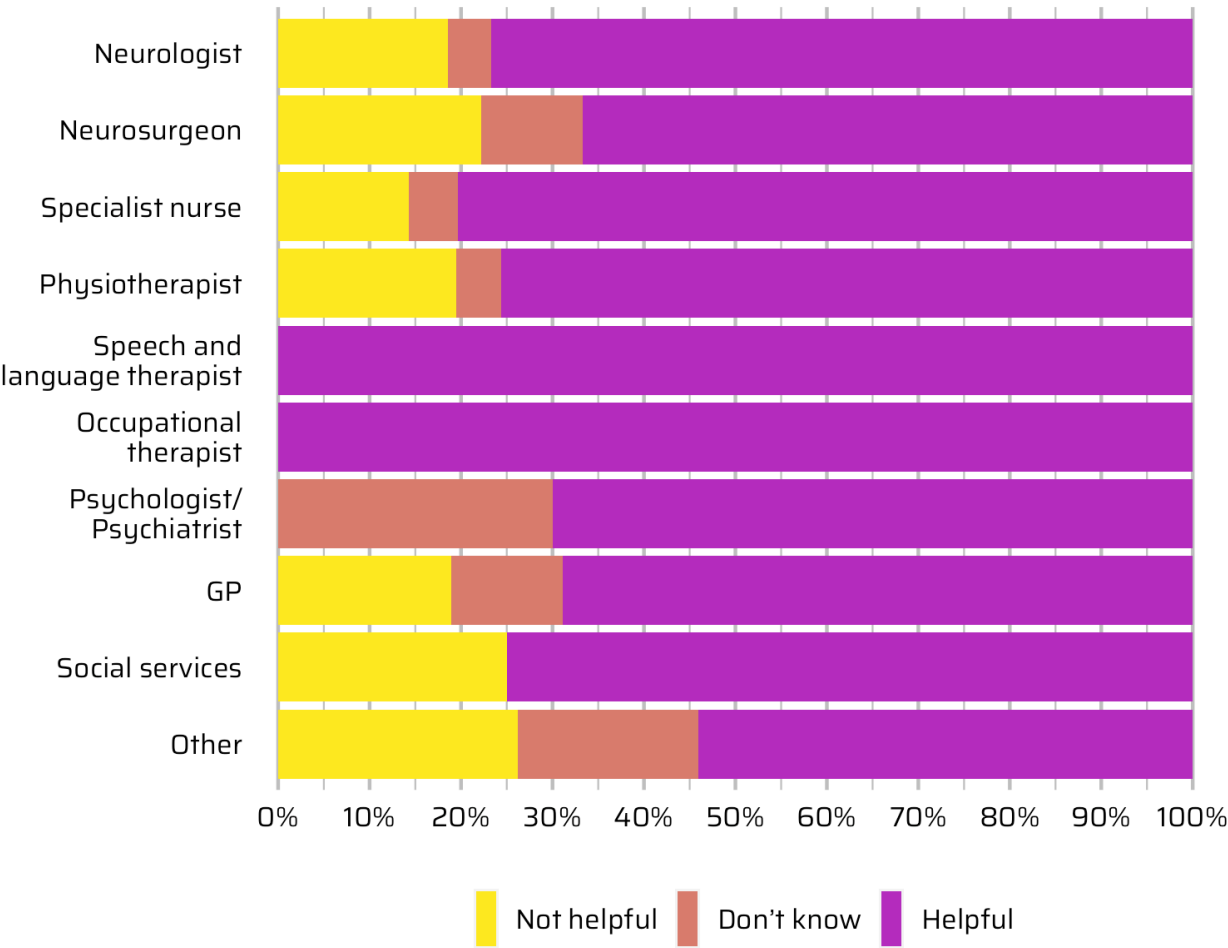


Table 37: Helpfulness of appointment by specialty

Specialty	Helpfulness	Observations	Percentage
Neurologist	Helpful	33	77
Neurologist	Don't know	2	5
Neurologist	Not helpful	8	19
Neurosurgeon	Helpful	6	67
Neurosurgeon	Don't know	1	11
Neurosurgeon	Not helpful	2	22
Specialist nurse	Helpful	45	80
Specialist nurse	Don't know	3	5
Specialist nurse	Not helpful	8	14
Physiotherapist	Helpful	31	76
Physiotherapist	Don't know	2	5
Physiotherapist	Not helpful	8	20
Speech and language therapist	Helpful	7	100
Speech and language therapist	Don't know	0	0
Speech and language therapist	Not helpful	0	0
Occupational therapist	Helpful	7	100
Occupational therapist	Don't know	0	0
Occupational therapist	Not helpful	0	0
Psychologist/Psychiatrist	Helpful	7	70
Psychologist/Psychiatrist	Don't know	3	30
Psychologist/Psychiatrist	Not helpful	0	0
GP	Helpful	51	69
GP	Don't know	9	12
GP	Not helpful	14	19
Social services	Helpful	3	75
Social services	Don't know	0	0
Social services	Not helpful	1	25
Other	Helpful	33	54
Other	Don't know	12	20
Other	Not helpful	16	26

Figure 38: Mode of delivery

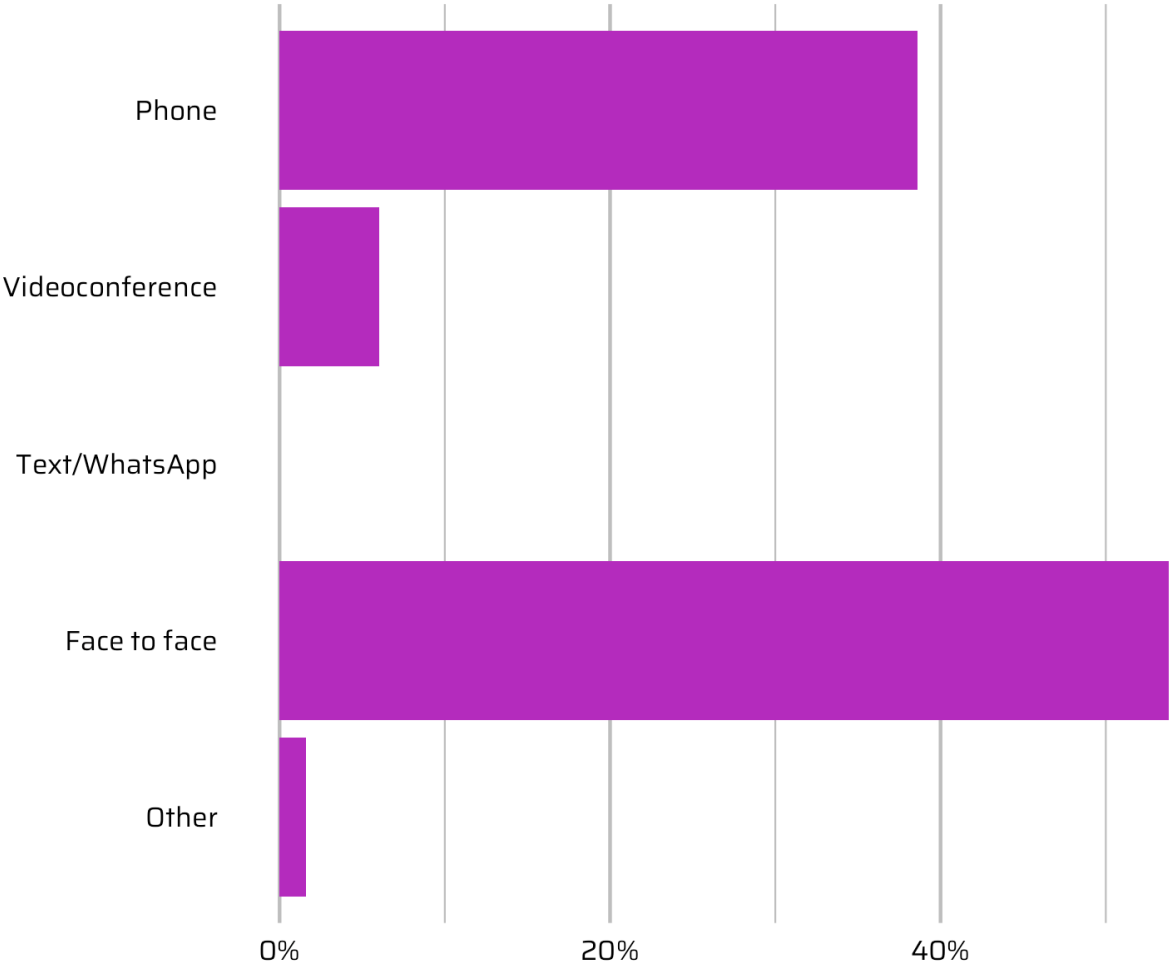


Table 38: Mode of delivery

Mode	Observations	Percentage
Phone	122	39
Videoconference	19	6
Text/WhatsApp	0	0
Face to face	170	54
Other	5	2

Figure 39: Helpfulness by mode of delivery

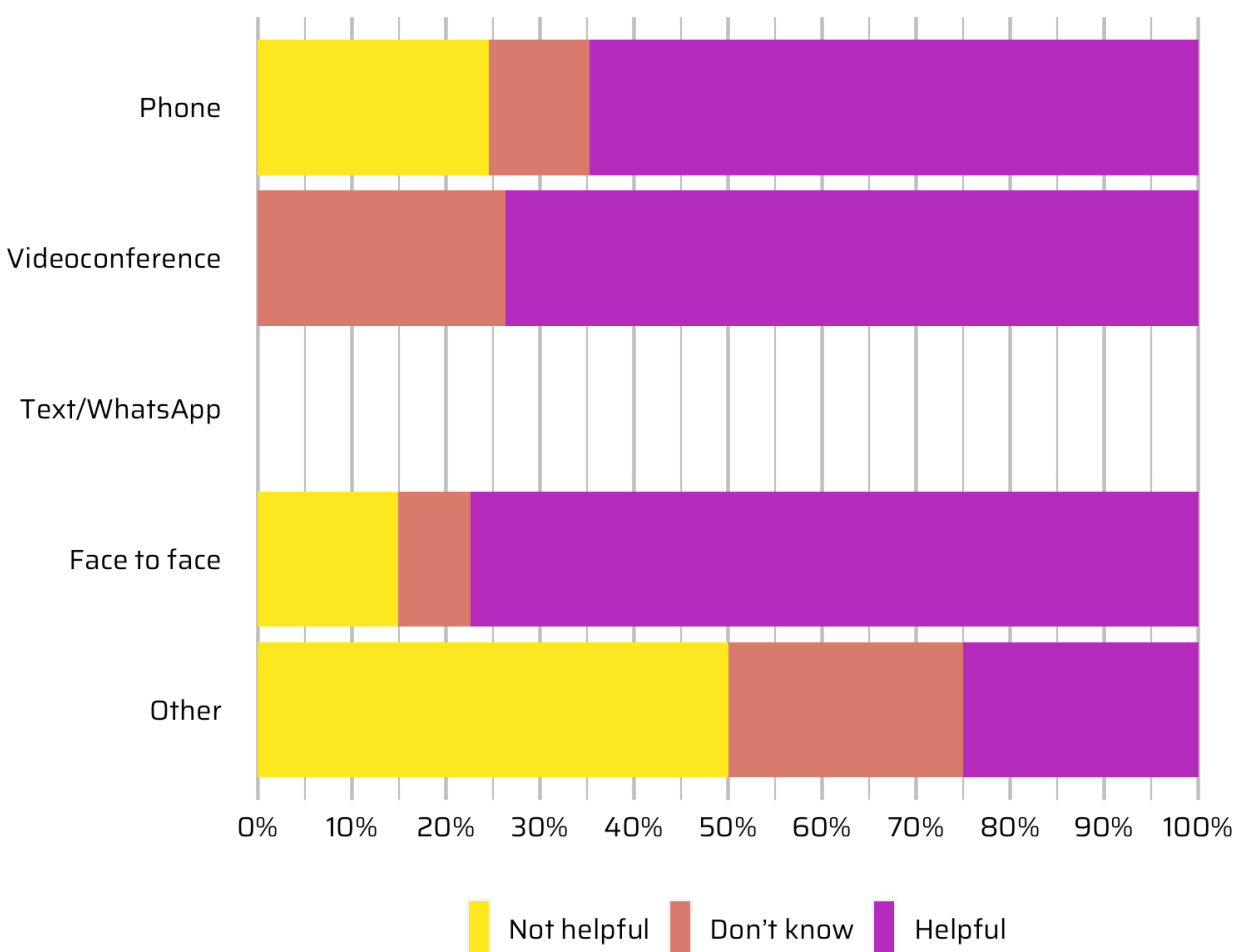


Table 39: Helpfulness by mode of delivery

Mode	Helpfulness	Observations	Percentage
Phone	Helpful	79	65
Phone	Don't know	13	11
Phone	Not helpful	30	25
Videoconference	Helpful	14	74
Videoconference	Don't know	5	26
Videoconference	Not helpful	0	0
Text/WhatsApp	Helpful	0	NaN
Text/WhatsApp	Don't know	0	NaN
Text/WhatsApp	Not helpful	0	NaN
Face to face	Helpful	130	77
Face to face	Don't know	13	8
Face to face	Not helpful	25	15
Other	Helpful	1	25
Other	Don't know	1	25

Other	Not helpful	2	50
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Access to mental health support

Figure 40: To what extent are your mental health needs being met?

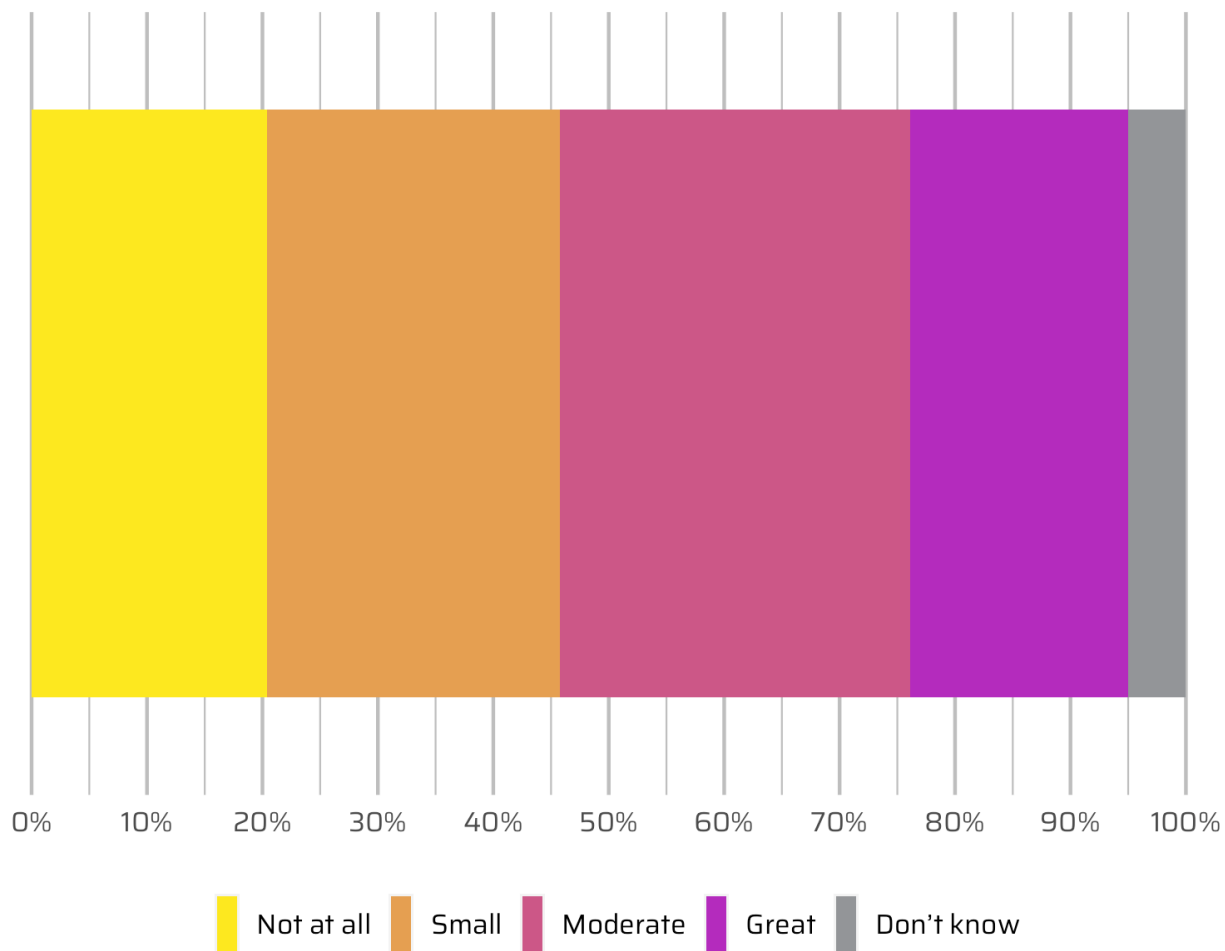


Table 40: No. and type of responses to the question 'To what extent do you feel your mental health needs are being met?'

Extent	Respondents	Percentage
Great	38	19
Moderate	61	30
Small	51	25
Not at all	41	20
Don't know	10	5

Figure 41: Mental health needs met by gender

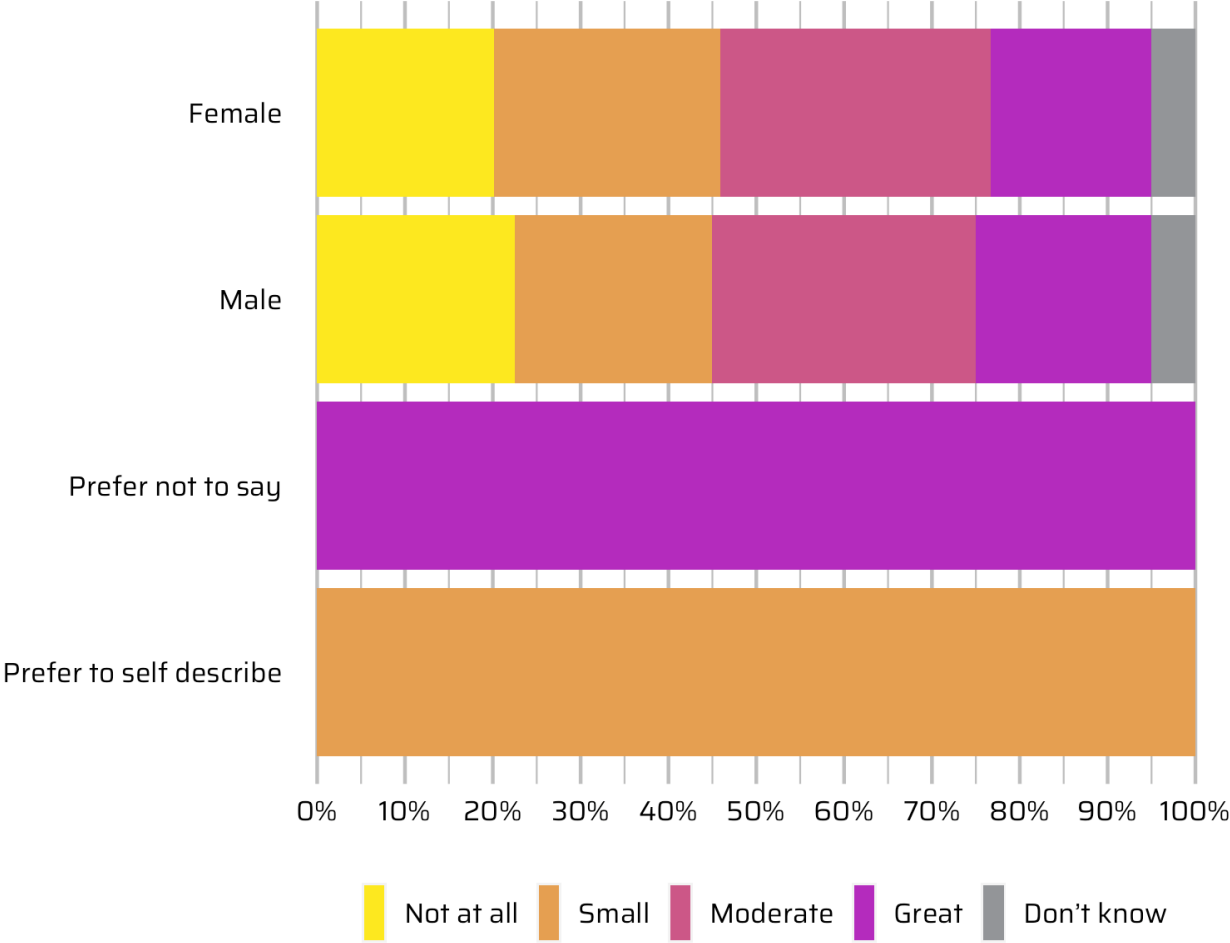


Table 41: No. and type of responses to the question 'To what extent do you feel your mental health needs are being met?' by gender

Gender	Extent	Respondents	Percentage
Female	Great	29	18
Female	Moderate	49	31
Female	Small	41	26
Female	Not at all	32	20
Female	Don't know	8	5
Male	Great	8	20
Male	Moderate	12	30
Male	Small	9	22
Male	Not at all	9	22
Male	Don't know	2	5
Prefer not to say	Great	1	100
Prefer not to say	Moderate	0	0
Prefer not to say	Small	0	0
Prefer not to say	Not at all	0	0
Prefer not to say	Don't know	0	0
Prefer to self describe	Great	0	0
Prefer to self describe	Moderate	0	0
Prefer to self describe	Small	1	100
Prefer to self describe	Not at all	0	0
Prefer to self describe	Don't know	0	0

Figure 42: Mental Health Needs Met by employment status

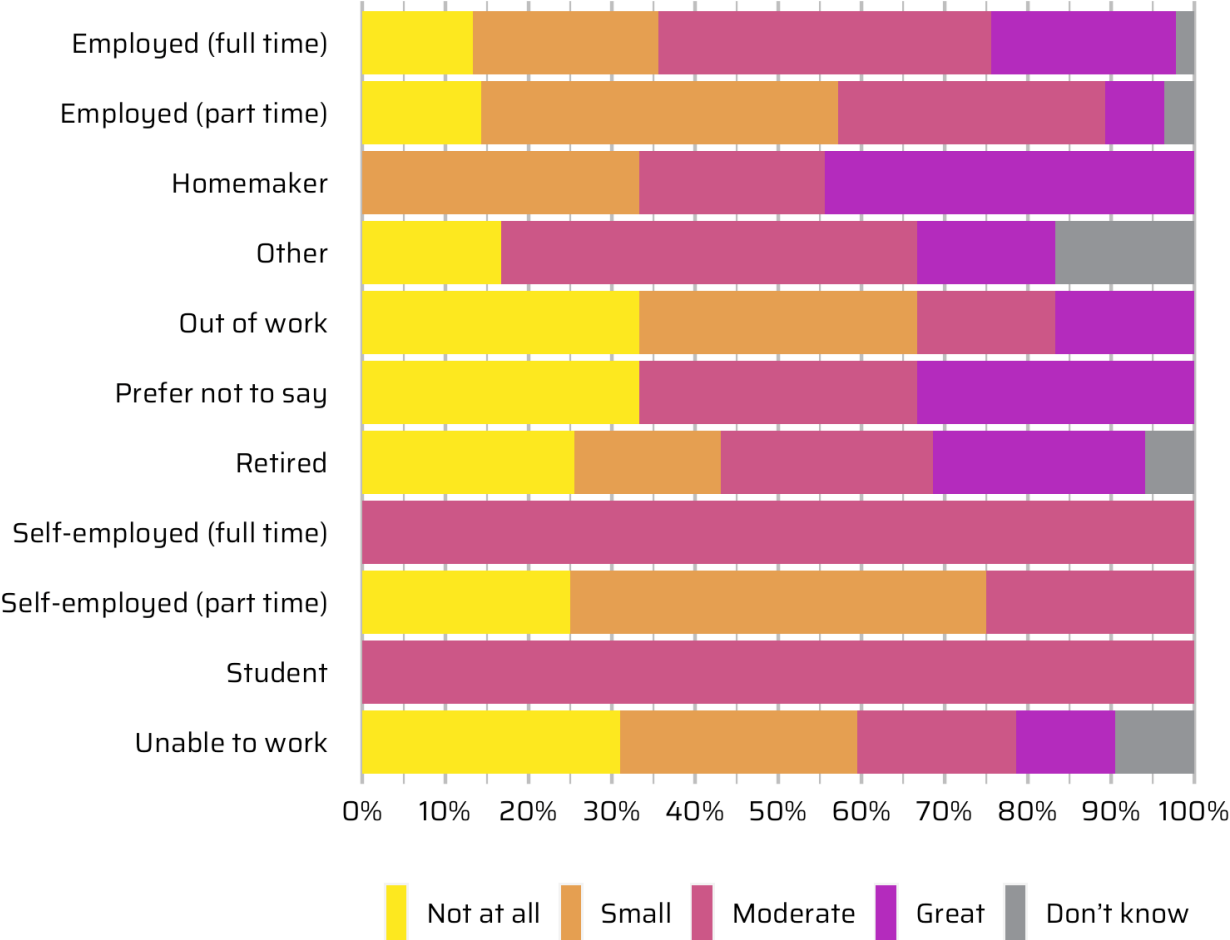


Table 42: No. and type of responses to the question 'To what extent do you feel your mental health needs are being met?' by employment status

Employment Status	Extent	Respondents	Percentage
Employed (full time)	Great	10	22
Employed (full time)	Moderate	18	40
Employed (full time)	Small	10	22
Employed (full time)	Not at all	6	13
Employed (full time)	Don't know	1	2
Employed (part time)	Great	2	7
Employed (part time)	Moderate	9	32
Employed (part time)	Small	12	43
Employed (part time)	Not at all	4	14
Employed (part time)	Don't know	1	4
Homemaker	Great	4	44
Homemaker	Moderate	2	22
Homemaker	Small	3	33
Homemaker	Not at all	0	0
Homemaker	Don't know	0	0
Other	Great	1	17
Other	Moderate	3	50
Other	Small	0	0
Other	Not at all	1	17
Other	Don't know	1	17
Out of work	Great	1	17
Out of work	Moderate	1	17
Out of work	Small	2	33
Out of work	Not at all	2	33
Out of work	Don't know	0	0
Prefer not to say	Great	1	33
Prefer not to say	Moderate	1	33
Prefer not to say	Small	0	0
Prefer not to say	Not at all	1	33
Prefer not to say	Don't know	0	0
Retired	Great	13	25
Retired	Moderate	13	25
Retired	Small	9	18
Retired	Not at all	13	25
Retired	Don't know	3	6

Self-employed (full time)	Great	0	0
Self-employed (full time)	Moderate	3	100
Self-employed (full time)	Small	0	0
Self-employed (full time)	Not at all	0	0
Self-employed (full time)	Don't know	0	0
Self-employed (part time)	Great	0	0
Self-employed (part time)	Moderate	1	25
Self-employed (part time)	Small	2	50
Self-employed (part time)	Not at all	1	25
Self-employed (part time)	Don't know	0	0
Student	Great	0	0
Student	Moderate	1	100
Student	Small	0	0
Student	Not at all	0	0
Student	Don't know	0	0
Unable to work	Great	5	12
Unable to work	Moderate	8	19
Unable to work	Small	12	29
Unable to work	Not at all	13	31
Unable to work	Don't know	4	10

Figure 43: Number of Dependents by Mental Health Needs Met

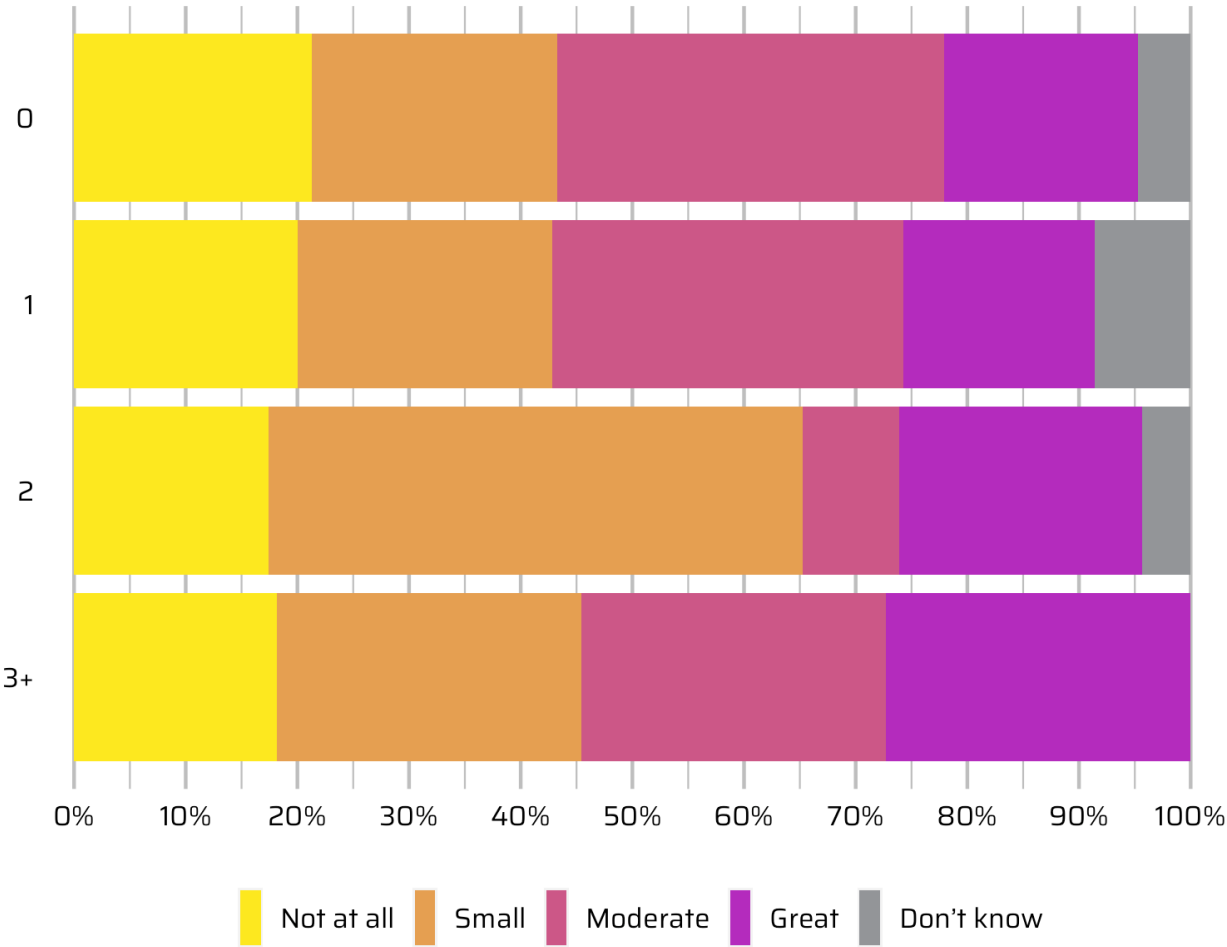


Table 43: No. and type of responses to the question 'To what extent do you feel your mental health needs are being met?' by number of dependents

Dependents	Extent	Respondents	Percentage
0	Great	22	17
0	Moderate	44	35
0	Small	28	22
0	Not at all	27	21
0	Don't know	6	5
1	Great	6	17
1	Moderate	11	31
1	Small	8	23
1	Not at all	7	20
1	Don't know	3	9
2	Great	5	22
2	Moderate	2	9
2	Small	11	48
2	Not at all	4	17
2	Don't know	1	4
3+	Great	3	27
3+	Moderate	3	27
3+	Small	3	27
3+	Not at all	2	18
3+	Don't know	0	0

Figure 44: Mental health needs met by marital status

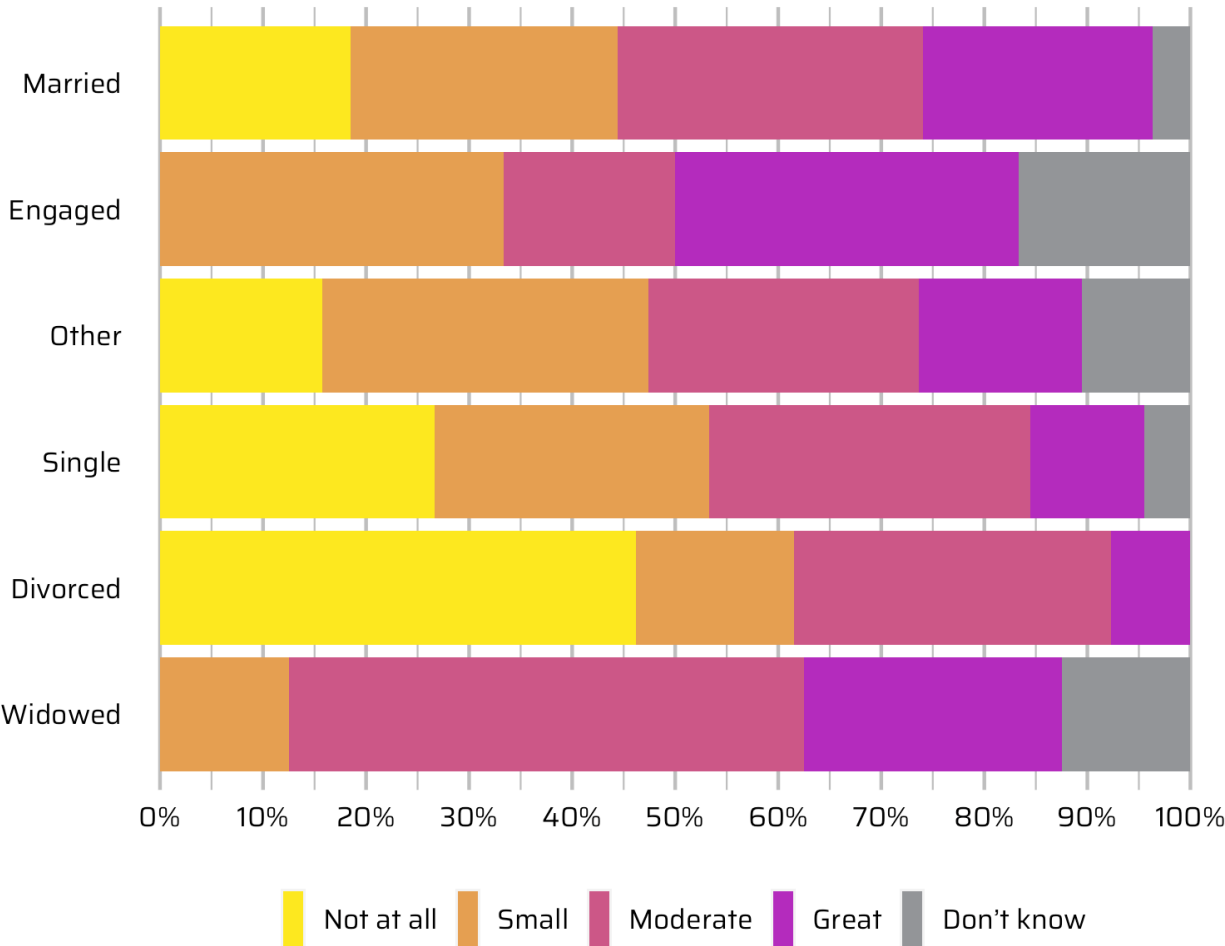


Table 44: No. and type of responses to the question 'To what extent do you feel your mental health needs are being met?' by marital status

Marital Status	Extent	Respondents	Percentage
Married	Great	24	22
Married	Moderate	32	30
Married	Small	28	26
Married	Not at all	20	19
Married	Don't know	4	4
Engaged	Great	2	33
Engaged	Moderate	1	17
Engaged	Small	2	33
Engaged	Not at all	0	0
Engaged	Don't know	1	17
Other	Great	3	16
Other	Moderate	5	26
Other	Small	6	32
Other	Not at all	3	16
Other	Don't know	2	11
Single	Great	5	11
Single	Moderate	14	31
Single	Small	12	27
Single	Not at all	12	27
Single	Don't know	2	4
Divorced	Great	1	8
Divorced	Moderate	4	31
Divorced	Small	2	15
Divorced	Not at all	6	46
Divorced	Don't know	0	0
Widowed	Great	2	25
Widowed	Moderate	4	50
Widowed	Small	1	12
Widowed	Not at all	0	0
Widowed	Don't know	1	12

Figure 45: Anxious or hopeless feeling

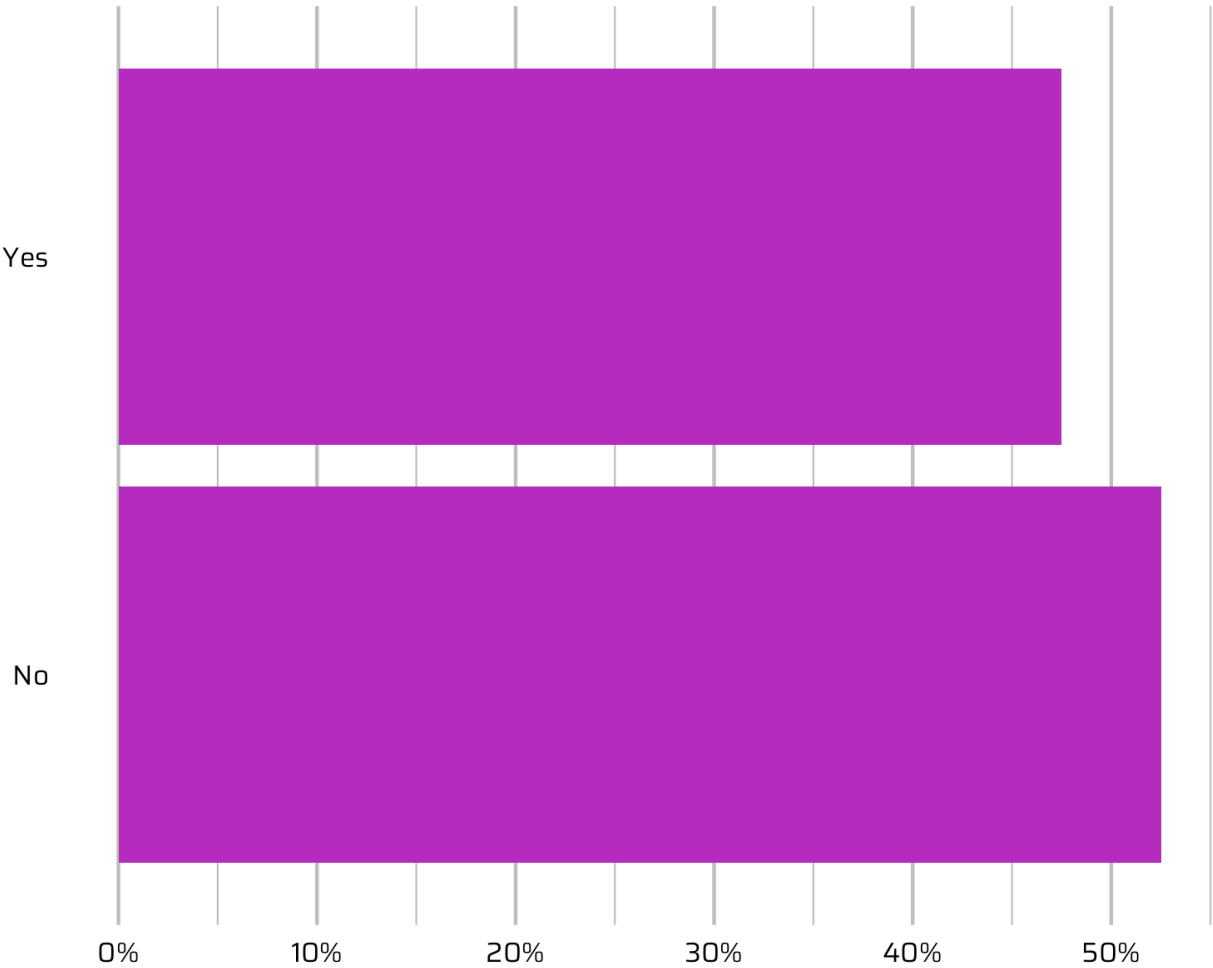


Table 45: Anxious or hopeless feeling

Anxious or Hopeless	Respondents	Percentage
Yes	95	48
No	105	52

Figure 46: Anxious or hopeless feeling by ethnicity

Table 46: Anxious or hopeless feeling by ethnicity

Figure 47: Anxious or hopeless feeling by marital status

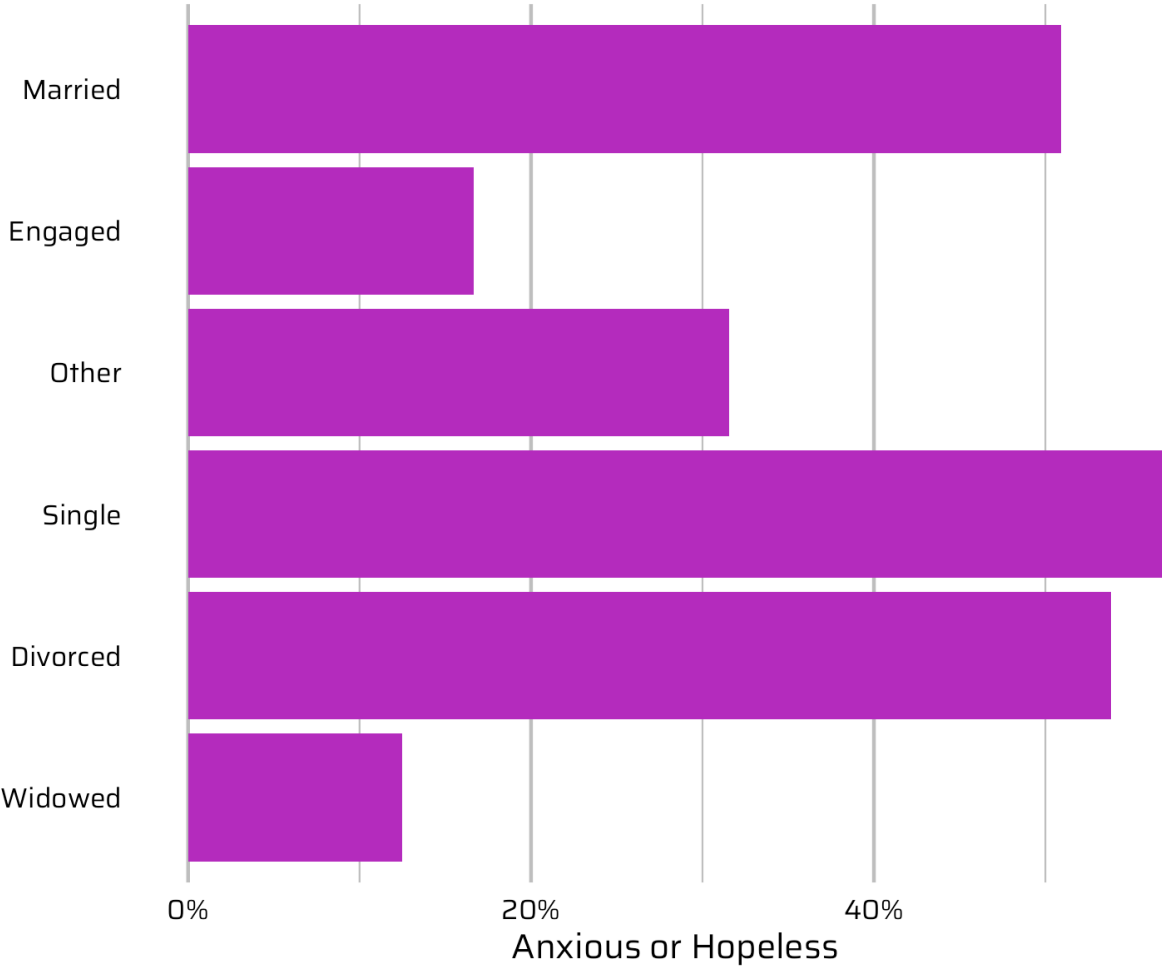


Table 47: Anxious or hopeless feeling by marital status

Marital Status	Anxious or Hopeless	Respondents	Percentage
Married	Yes	55	51
Married	No	53	49
Engaged	Yes	1	17
Engaged	No	5	83
Other	Yes	6	32
Other	No	13	68
Single	Yes	25	57
Single	No	19	43
Divorced	Yes	7	54
Divorced	No	6	46
Widowed	Yes	1	12
Widowed	No	7	88

Figure 48: Anxious or hopeless feeling by employment status

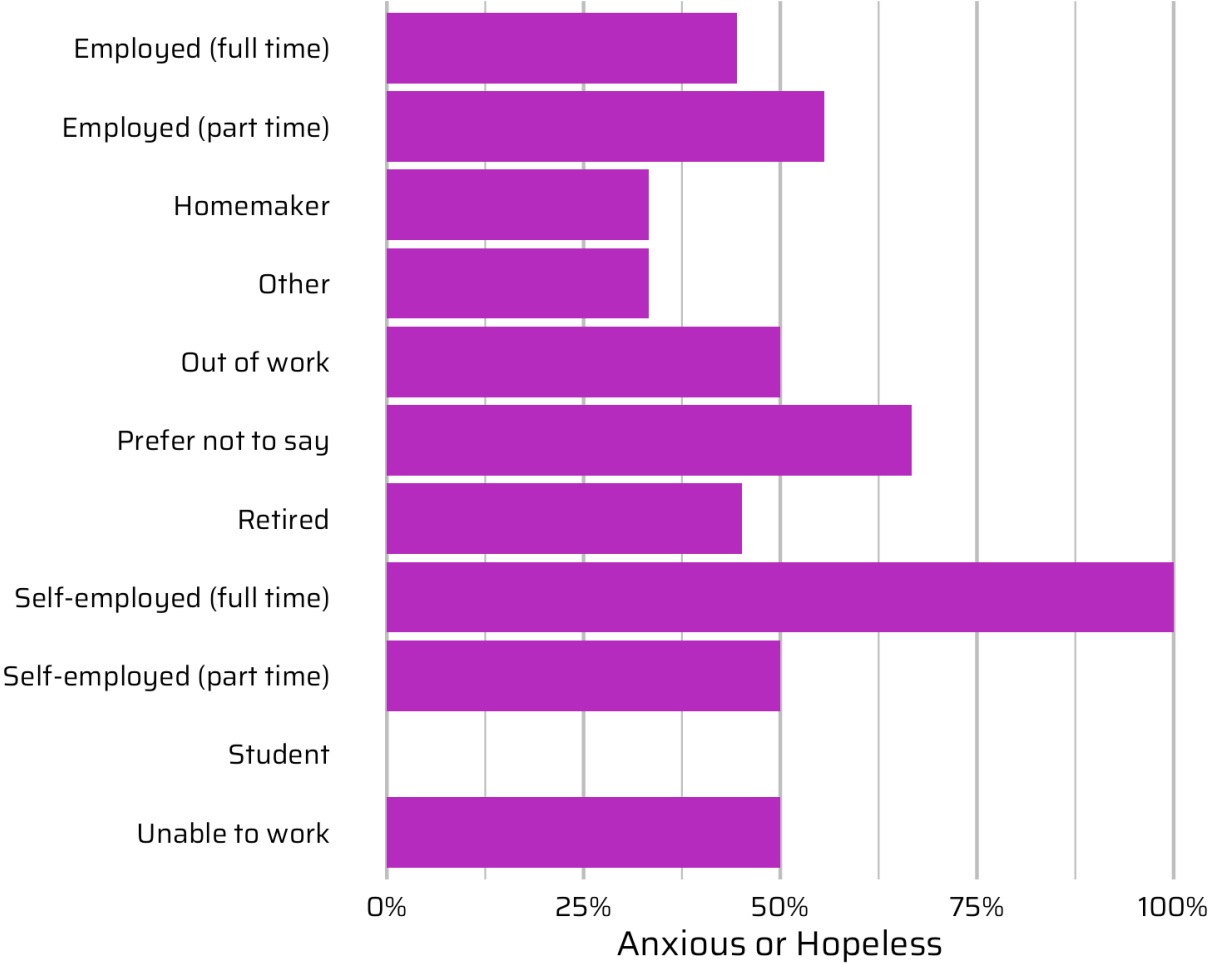


Table 48: Anxious or hopeless feeling by employment status

Employment Status	Anxious or Hopeless	Respondents	Percentage
Employed (full time)	Yes	20	44
Employed (full time)	No	25	56
Employed (part time)	Yes	15	56
Employed (part time)	No	12	44
Homemaker	Yes	3	33
Homemaker	No	6	67
Other	Yes	2	33
Other	No	4	67
Out of work	Yes	3	50
Out of work	No	3	50
Prefer not to say	Yes	2	67
Prefer not to say	No	1	33
Retired	Yes	23	45
Retired	No	28	55
Self-employed (full time)	Yes	3	100
Self-employed (full time)	No	0	0
Self-employed (part time)	Yes	2	50
Self-employed (part time)	No	2	50
Student	Yes	0	0
Student	No	1	100
Unable to work	Yes	21	50
Unable to work	No	21	50

Figure 49: Anxious or hopeless feeling by financial status

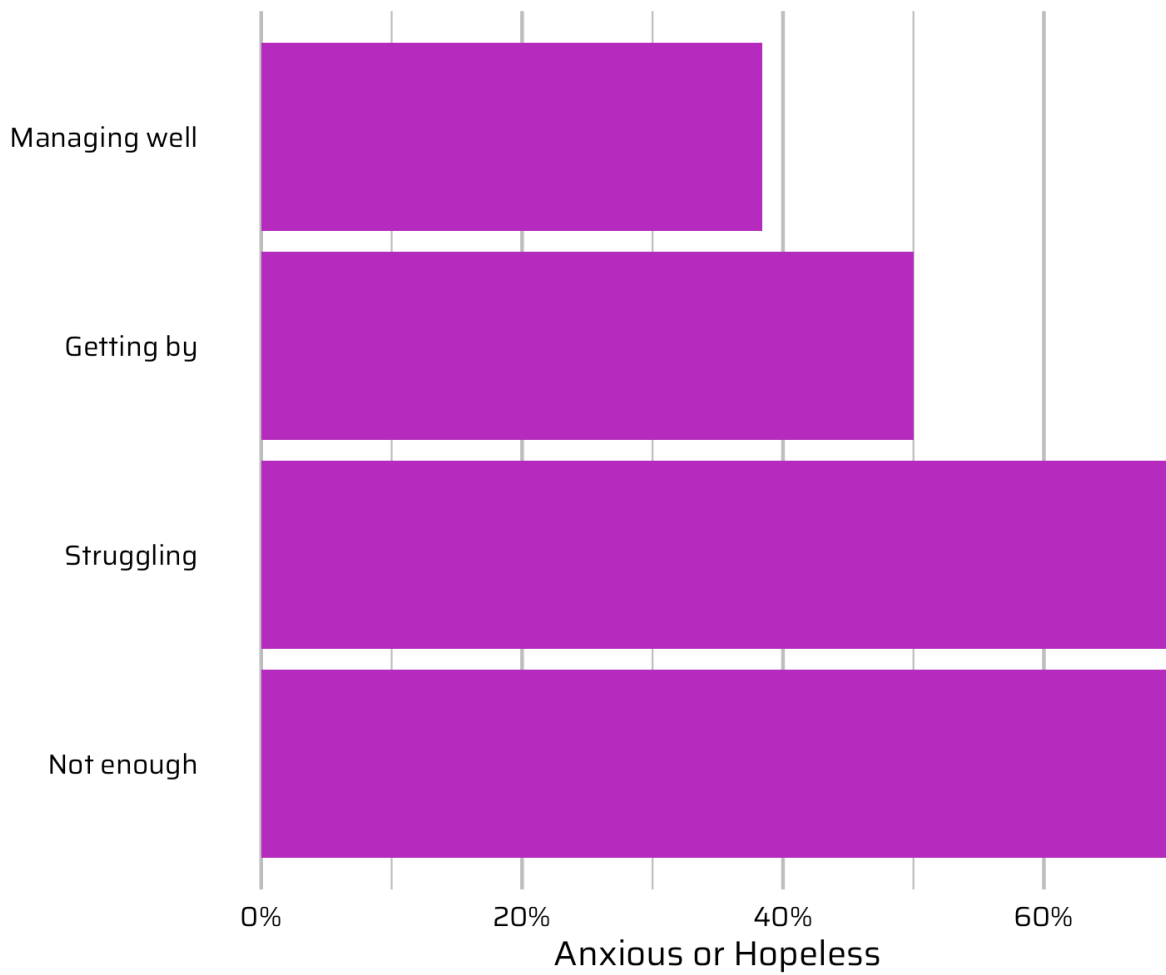


Table 49: Anxious or hopeless feeling by financial status

Financial Status	Anxious or Hopeless	Respondents	Percentage
Managing well	Yes	38	38
Managing well	No	61	62
Getting by	Yes	34	50
Getting by	No	34	50
Struggling	Yes	16	70
Struggling	No	7	30
Not enough	Yes	7	70
Not enough	No	3	30

Figure 50: Anxious or Hopeless Feeling by Mental Health Needs Met

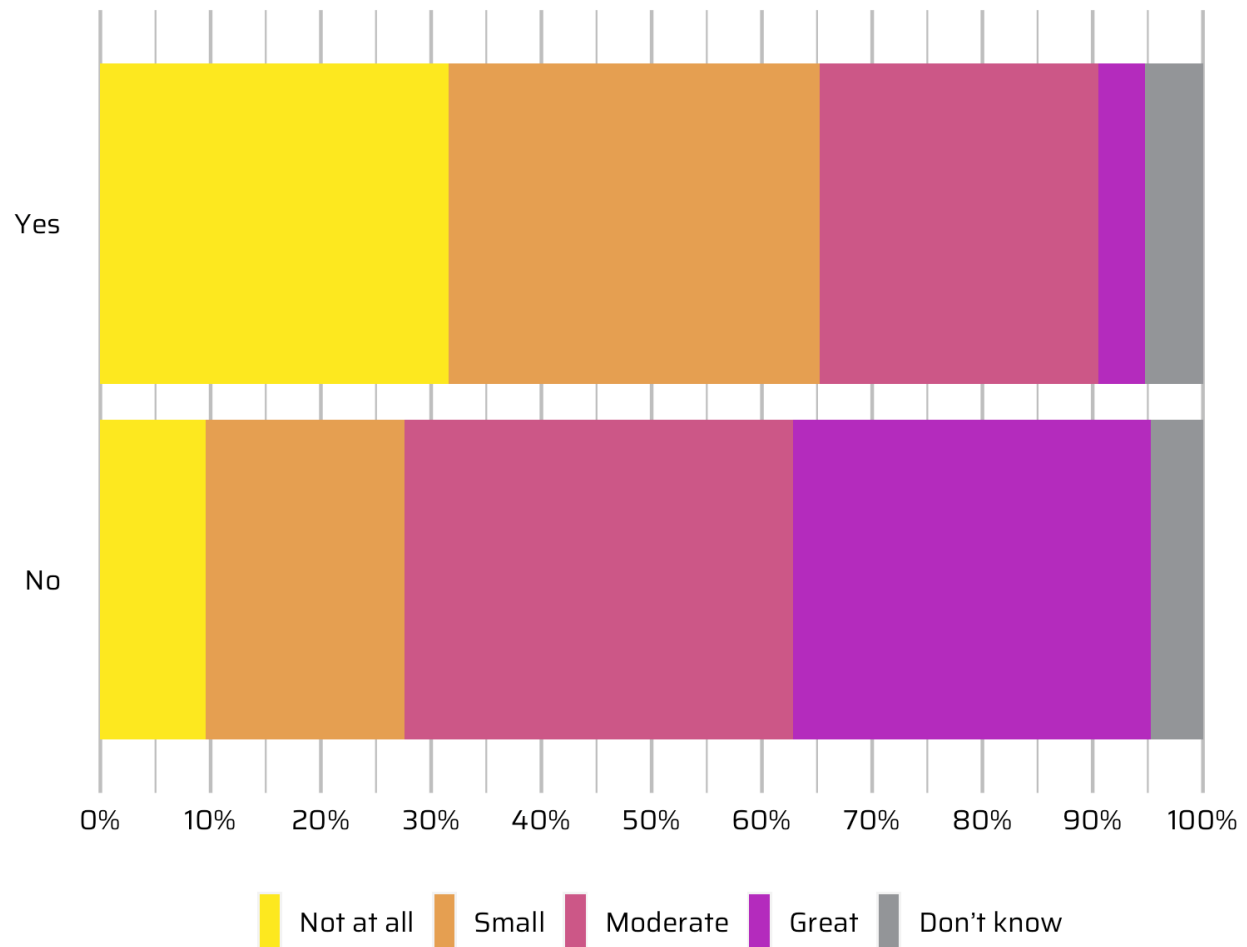


Table 50: No. and type of responses to the question 'To what extent do you feel your mental health needs are being met?' by feelings of anxiety or hopelessness

Anxious or Hopeless	Extent	Respondents	Percentage
Yes	Great	4	4
Yes	Moderate	24	25
Yes	Small	32	34
Yes	Not at all	30	32
Yes	Don't know	5	5
No	Great	34	32
No	Moderate	37	35
No	Small	19	18
No	Not at all	10	10
No	Don't know	5	5

Figure 51: Delay to Care by the Extent Mental Health Needs Met

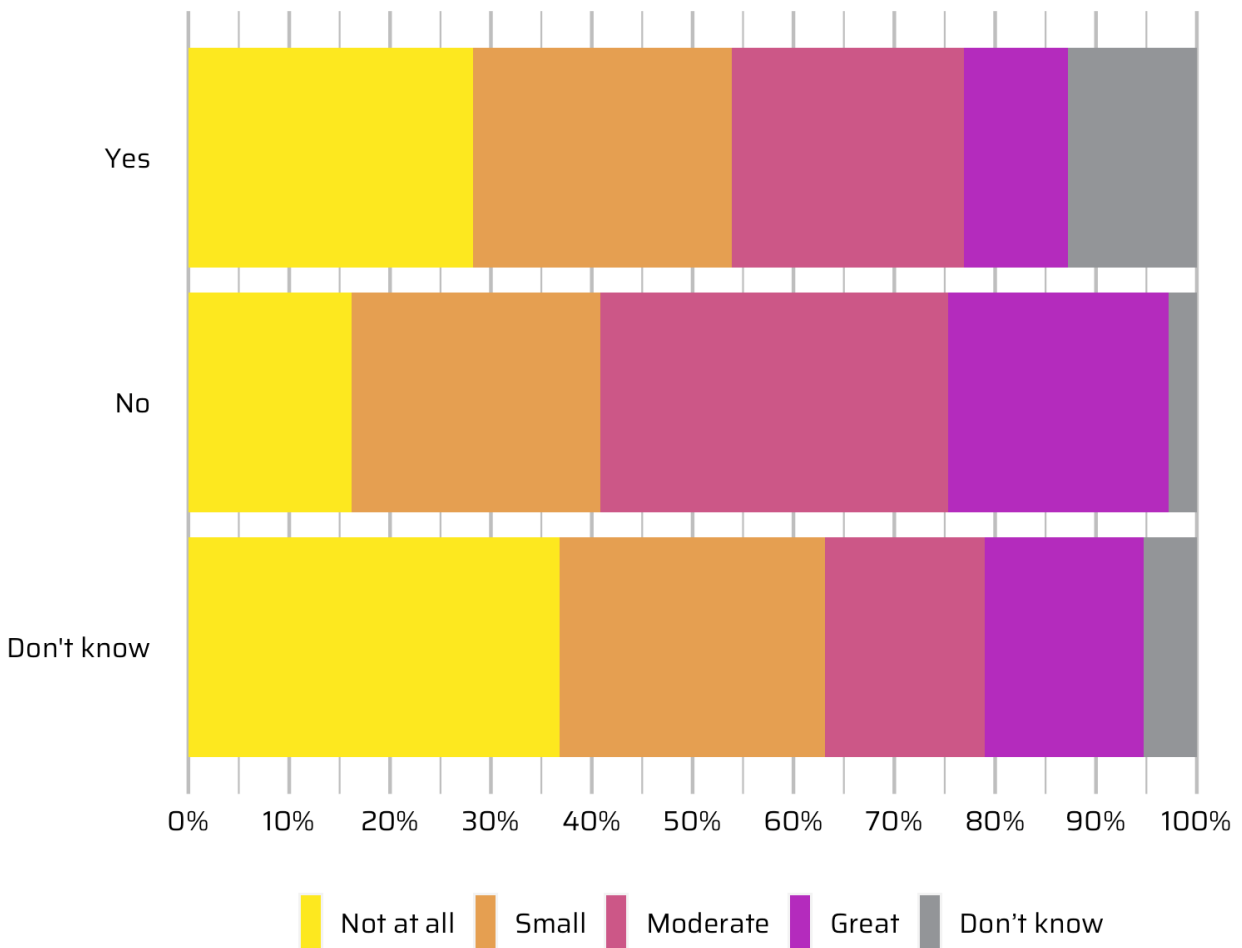


Table 51: No. and type of responses to the question 'To what extent do you feel your mental health needs are being met?' by delays to care

Delay	Extent	Respondents	Percentage
Yes	Great	4	10
Yes	Moderate	9	23
Yes	Small	10	26
Yes	Not at all	11	28
Yes	Don't know	5	13
No	Great	31	22
No	Moderate	49	35
No	Small	35	25
No	Not at all	23	16
No	Don't know	4	3
Don't know	Great	3	16

Don't know	Moderate	3	16
Don't know	Small	5	26
Don't know	Not at all	7	37
Don't know	Don't know	1	5

Figure 52: Cancellation of Care by the Extent Mental Health Needs Met

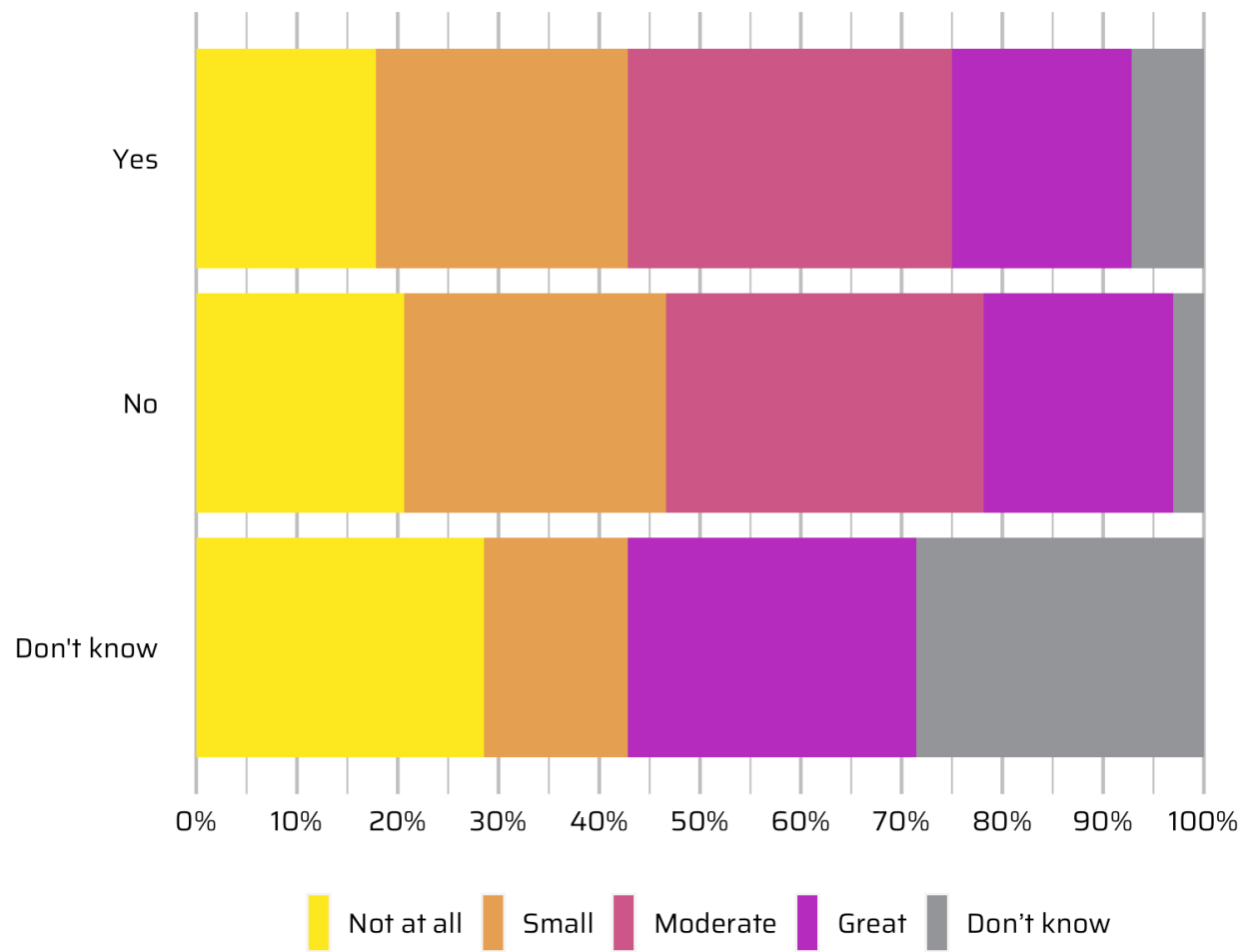


Table 52: No. and type of responses to the question 'To what extent do you feel your mental health needs are being met?' by cancellation of care

Cancellation	Extent	Respondents	Percentage
Yes	Great	5	18
Yes	Moderate	9	32
Yes	Small	7	25
Yes	Not at all	5	18
Yes	Don't know	2	7
No	Great	31	19
No	Moderate	52	32
No	Small	43	26
No	Not at all	34	21
No	Don't know	5	3
Don't know	Great	2	29
Don't know	Moderate	0	0
Don't know	Small	1	14
Don't know	Not at all	2	29
Don't know	Don't know	2	29

Figure 53: Financial Status by Extent Mental Health Needs Met

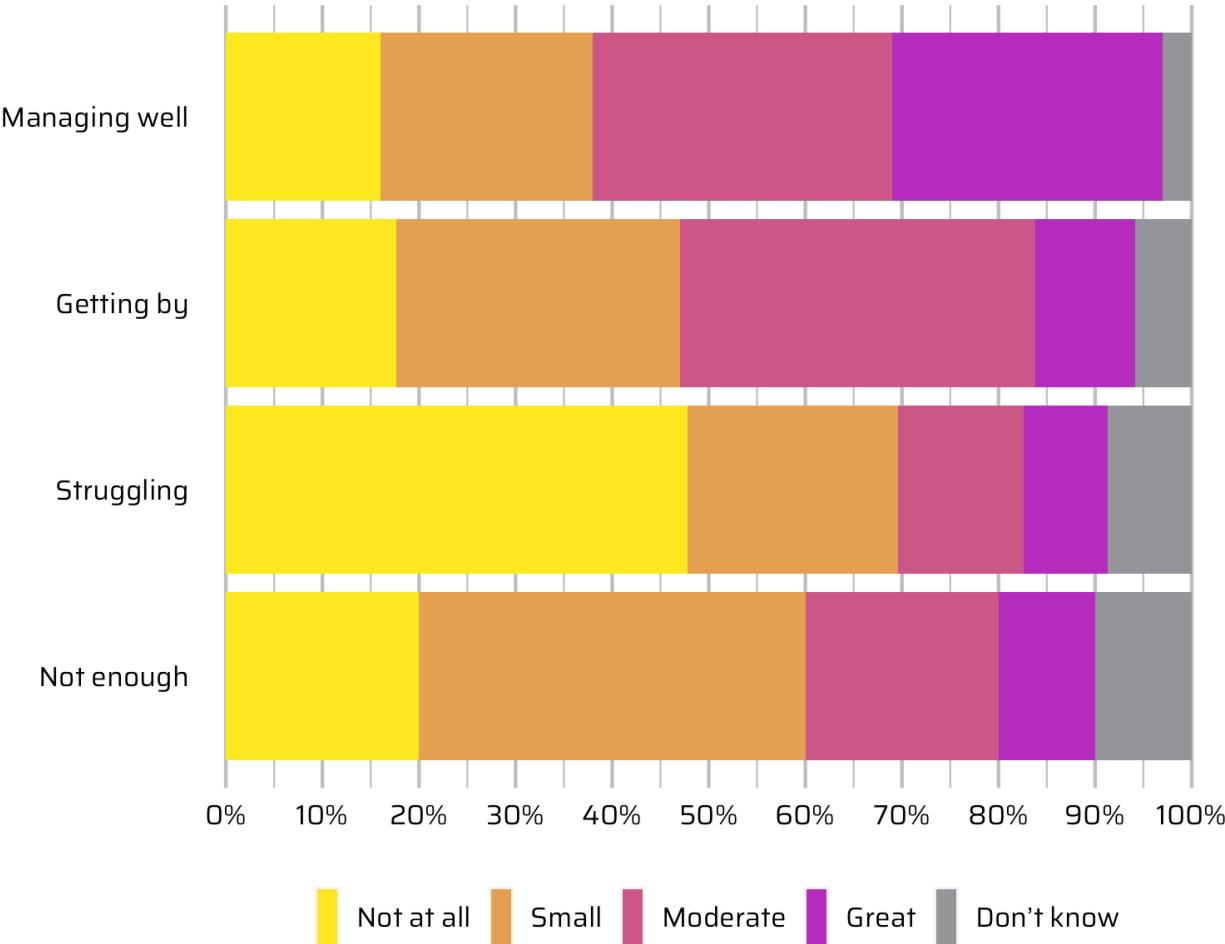


Table 53: No. and type of responses to the question 'To what extent do you feel your mental health needs are being met?' by financial status

Financial Status	Extent	Respondents	Percentage
Managing well	Great	28	28
Managing well	Moderate	31	31
Managing well	Small	22	22
Managing well	Not at all	16	16
Managing well	Don't know	3	3
Getting by	Great	7	10
Getting by	Moderate	25	37
Getting by	Small	20	29
Getting by	Not at all	12	18
Getting by	Don't know	4	6
Struggling	Great	2	9
Struggling	Moderate	3	13
Struggling	Small	5	22
Struggling	Not at all	11	48
Struggling	Don't know	2	9
Not enough	Great	1	10
Not enough	Moderate	2	20
Not enough	Small	4	40
Not enough	Not at all	2	20
Not enough	Don't know	1	10

Figure 54: Age group and Extent Mental Health Needs Met

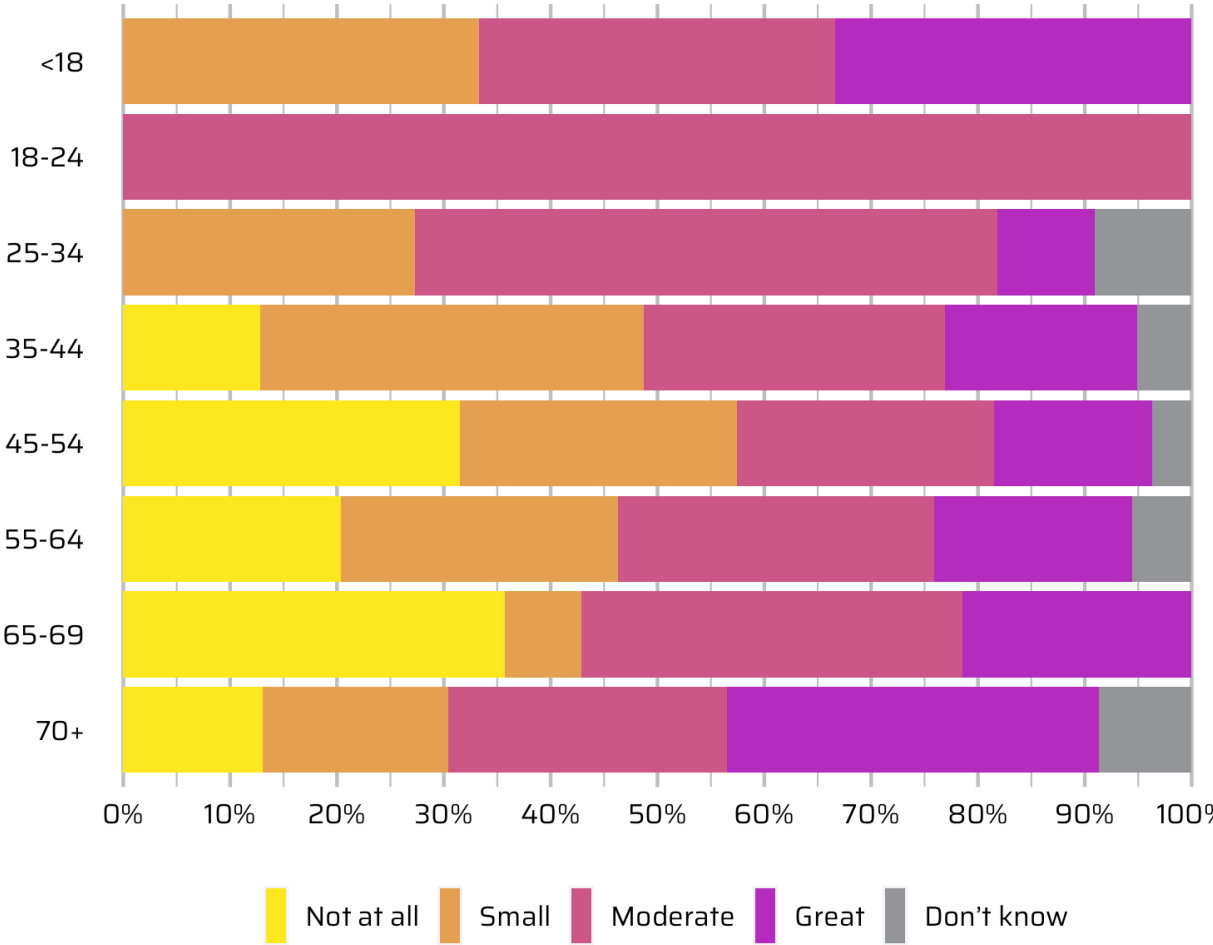


Table 54: No. and type of responses to the question 'To what extent do you feel your mental health needs are being met?' by age group

Age	Extent	Respondents	Percentage
<18	Great	1	33
<18	Moderate	1	33
<18	Small	1	33
<18	Not at all	0	0
<18	Don't know	0	0
18-24	Great	0	0
18-24	Moderate	3	100
18-24	Small	0	0
18-24	Not at all	0	0
18-24	Don't know	0	0
25-34	Great	1	9
25-34	Moderate	6	55
25-34	Small	3	27
25-34	Not at all	0	0
25-34	Don't know	1	9
35-44	Great	7	18
35-44	Moderate	11	28
35-44	Small	14	36
35-44	Not at all	5	13
35-44	Don't know	2	5
45-54	Great	8	15
45-54	Moderate	13	24
45-54	Small	14	26
45-54	Not at all	17	31
45-54	Don't know	2	4
55-64	Great	10	19
55-64	Moderate	16	30
55-64	Small	14	26
55-64	Not at all	11	20
55-64	Don't know	3	6
65-69	Great	3	21
65-69	Moderate	5	36
65-69	Small	1	7
65-69	Not at all	5	36
65-69	Don't know	0	0

70+	Great	8	35
70+	Moderate	6	26
70+	Small	4	17
70+	Not at all	3	13
70+	Don't know	2	9

Figure 55: Ethnicity and Extent Mental Health Needs Met

Table 55: No. and type of responses to the question ‘To what extent do you feel your mental health needs are being met?’ by ethnicity