



# NeuroLifeNow

## ANALYSIS REPORT

**November 2021**

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***"I was diagnosed with Functional Neurological Disorder (FND) two years ago and have had to fight for what little help I've received. At the moment I'm waiting on rehabilitation. I'm in pain constantly but my doctor doesn't know what to prescribe. I'm just so fed up of it all."***

## **Foreword**

Thank you for your continued contribution to the NeuroLifeNow research.

Across the UK, winter pressures are being felt by people with neurological conditions, health and care professionals and services. In the last few weeks, the NHS set out resilience plans in preparation for what is expected to be an extremely challenging winter. We are working hard to ensure your voice is being heard.

Understandably, anxieties about COVID-19 are again on the rise – we asked how people felt about COVID-19 restrictions lifting. 56% of you felt Government were lifting restrictions too quickly. The UK Government has put its faith in vaccine boosters to avoid restrictions this winter, whereas as close by as in Republic of Ireland, their Government has reintroduced some restrictions in the hope of curtailing a fourth wave.

In September, the Neurological Alliance of Scotland released a report revealing that only 41% of people with brain and spine conditions in Scotland had been able to access face-to-face healthcare since the start of the pandemic. And this month, a third of you told us reported a health or care appointment by phone. We believe you should receive an appointment type appropriate for your needs at the time.

The reality of living with a neurological condition that you shared this month provides further illustration of unmet needs. Nearly a quarter of you reported delays to care. More than 4 in 10 said your mental health needs were being met to a small extent or not at all. A quarter of you who reported an appointment with your GP said it was unhelpful. 11% said your experience of care this month was poor or very poor. The Brain & Spine Foundation's free, national Helpline is run by neuroscience-trained nurses who provide a trusted and safe space where you can seek professional insight and emotional support. Call 0808 808 1000 (Mon-Thurs, 9am – 4pm) or email [helpline@brainandspine.org.uk](mailto:helpline@brainandspine.org.uk).

In these early stages of the NeuroLifeNow programme, some of the biggest policy wins have been in England. However, we are sharing these insights with partners across the UK as part of our commitment to UK wide change. The Neurological Alliance of England sits on the NHS England and NHS Improvement elective care recovery taskforce, which advises Government on their recovery plan for hospital care. Because of the experiences you have shared via NeuroLifeNow we have been able to provide up to date evidence about the support and care you receive. Recognising the very real disruption of neurology and neurosurgery services, these two specialties have been included as priorities within NHS guidance for the recovery of specialised hospital services. It has meant your insights have been heard at the very highest levels of the NHS and will be used to influence decision makers in Scotland, Wales and Northern Ireland.

We are still very concerned about waiting times for neurology or neurosurgery appointments and we are continuing to track the rate of increase.

Your insight is absolutely central to secure improved treatment and support for people with neurological conditions. Thank you for continuing to contribute to this research.

**Marc Smith, CEO Brain and Spine Foundation**

**Georgina Carr, CEO Neurological Alliance (England)**

## Background

NeuroLifeNow is an app and website that supports people with neurological conditions to share experiences of their care in the last 8 weeks. In return, you 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, you can review the experiences of other people with neurological conditions too. The data in this report is derived from responses received between 1 September – 31 October 2021. The full questionnaire and data tables are available in the appendices.

## Key findings

- 197 people shared their experiences in September and October, with 78% female respondents and 21% male. 59 different neurological conditions and symptoms were represented in the survey. The top three conditions or symptoms represented were multiple sclerosis, subarachnoid hemorrhage and migraine.
- 56% of respondents said that they felt the Government were lifting COVID-19 restrictions too quickly.
- 11% of people felt their care was poor or very poor (17% in July and August)
- 45% of respondents said their mental health needs were being met to a small extent or not at all. 20% of those who reported no cancellation to their care said their mental health needs were not being met at all – this increases to 36% for those who reported cancellations.
- Overall, 80% of the medical appointments evaluated were considered helpful.
- 58% of those who reported a health or care appointment said it was conducted face to face, a third by phone and just 5% by video conference.
- Appointments with speech and language therapists and specialist nurses were considered most helpful.

## Next steps

Our priority this month has been to review progress made and undertake a technology review to address the feedback you have given over the last few months. This has included directly sending you the results, testing new questions in the survey, and gathering further feedback on your experience using the App.

We are looking for people to join a co-design panel to help directly shape the development of the App. If you'd like to be a part of this, then we'd love to hear from you. Alternatively, if you have ideas or issues you've been experiencing then let us know by emailing [support@neurolifenow.org](mailto:support@neurolifenow.org).

The experiences shared in this report have also been shared with the NHS England and NHS Improvement outpatient and neuroscience transformation teams, who are looking to drive up standards of care, as well as reduce unwarranted variation in both access and funding. The teams have both indicated the importance and value of the experiences shared via the platform.

## Appendix 1: Questionnaire

Question	Hint	Answer1	Answer2	Answer3	Answer4	Answer5	Answer6	Answer7	Answer8	Answer9	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 appointments (including remote appointments) have you had in the last eight weeks?		0	1	2	3	4	5	6 or more			
Who was your medical appointment with?	Tell us which health or care professional you had your first	Neurologist	Specialist nurse	Physiotherapist	Speech and language therapist	Occupational therapist	Psychologist/Psychiatrist	GP	Social services	Neurosurgeon	Other (please specify)

	appointment in the last 8 weeks with										
Other (please specify)		Other (please specify)									
How was your medical appointment delivered?	Tell us how you spoke with your medical professional	Phone	Videoconferenc	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 in the last 8 weeks?	This refers to procedures or appointments that have been cancelled and you do not know when they have been rescheduled until	Yes	No	Don't know							
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	This refers to procedures or appointments	Yes	No	Don't know							



procedures been delayed in the last 8 weeks?	that have been delayed and a new date has been set for them to go ahead										
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		It was better	It was the same	It was worse							

pandemic compared to before the pandemic?											
Please tell us why											

## Appendix 2: Data tables

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Demographics

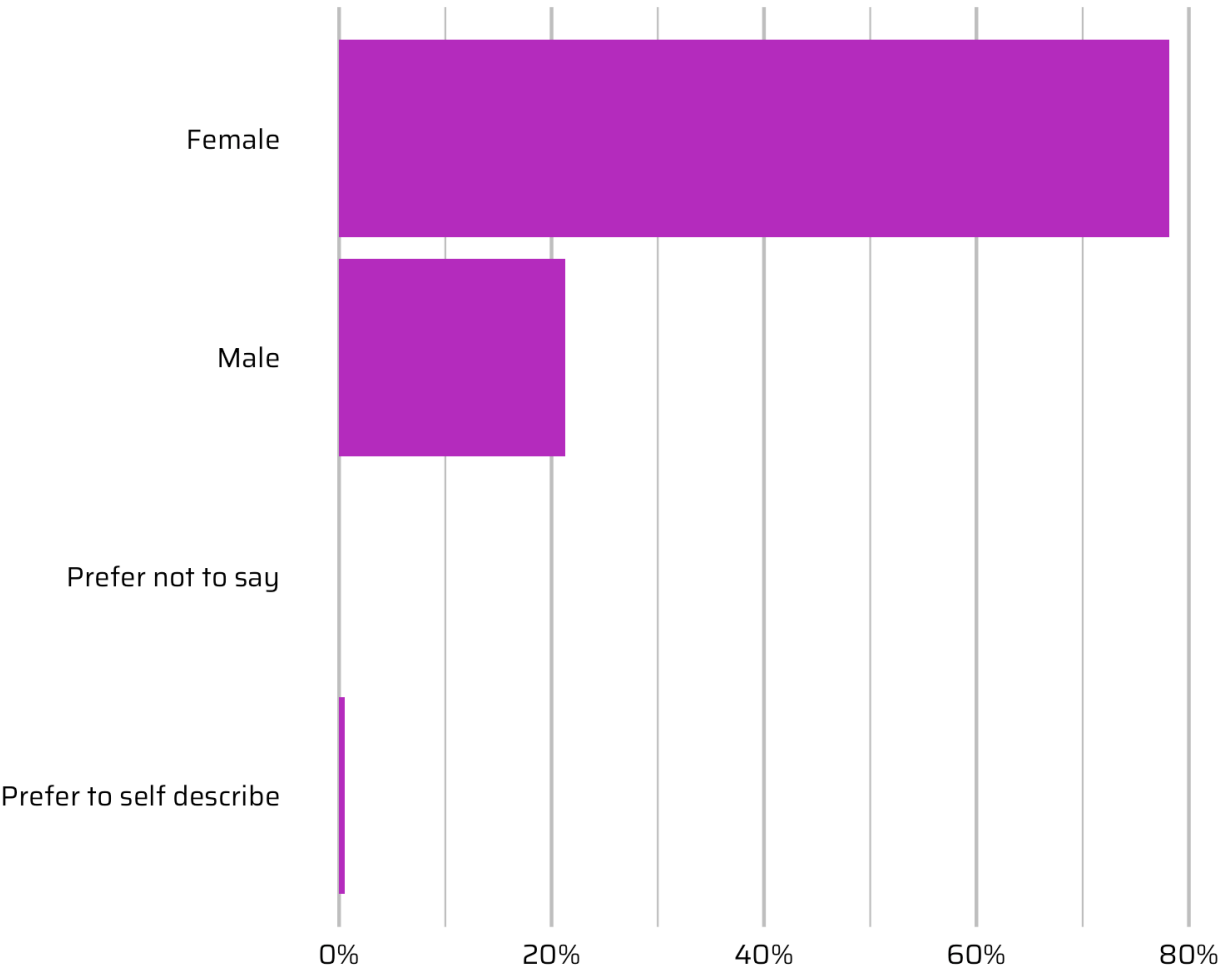
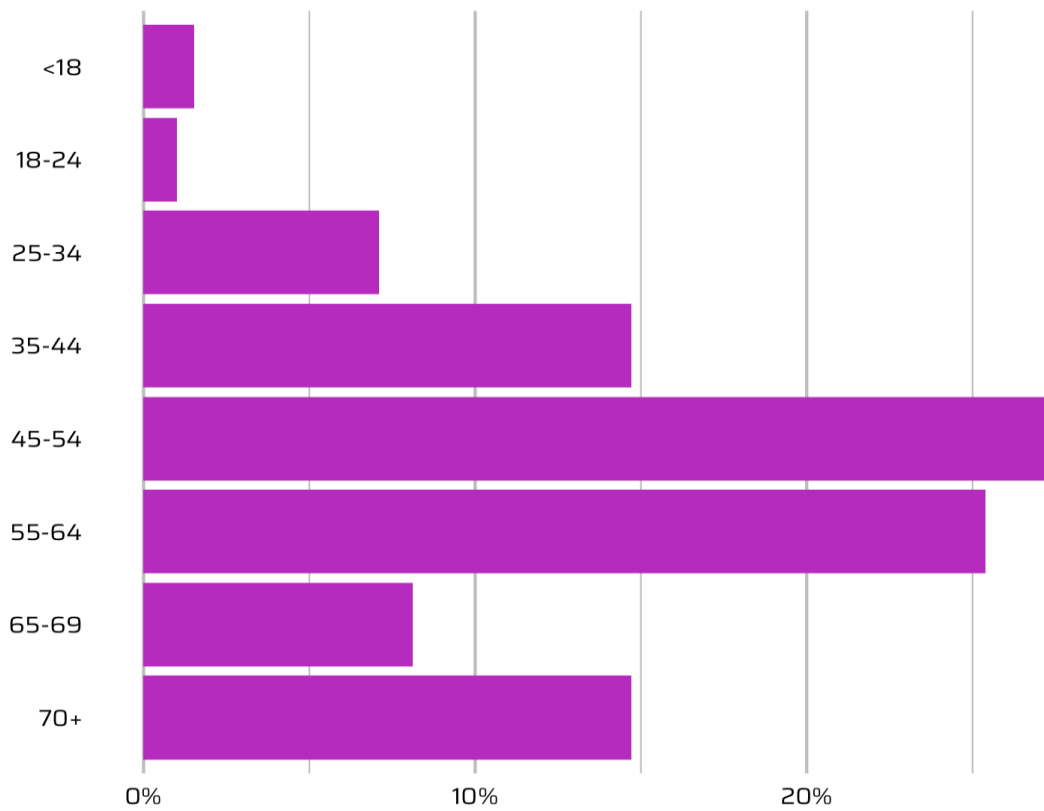


Figure 1: Gender of respondents

Table 1: Gender of respondents

Gender	Respondents	Percentage
Female	154	78
Male	42	21
Prefer not to say	0	0
Prefer to self-describe	1	1

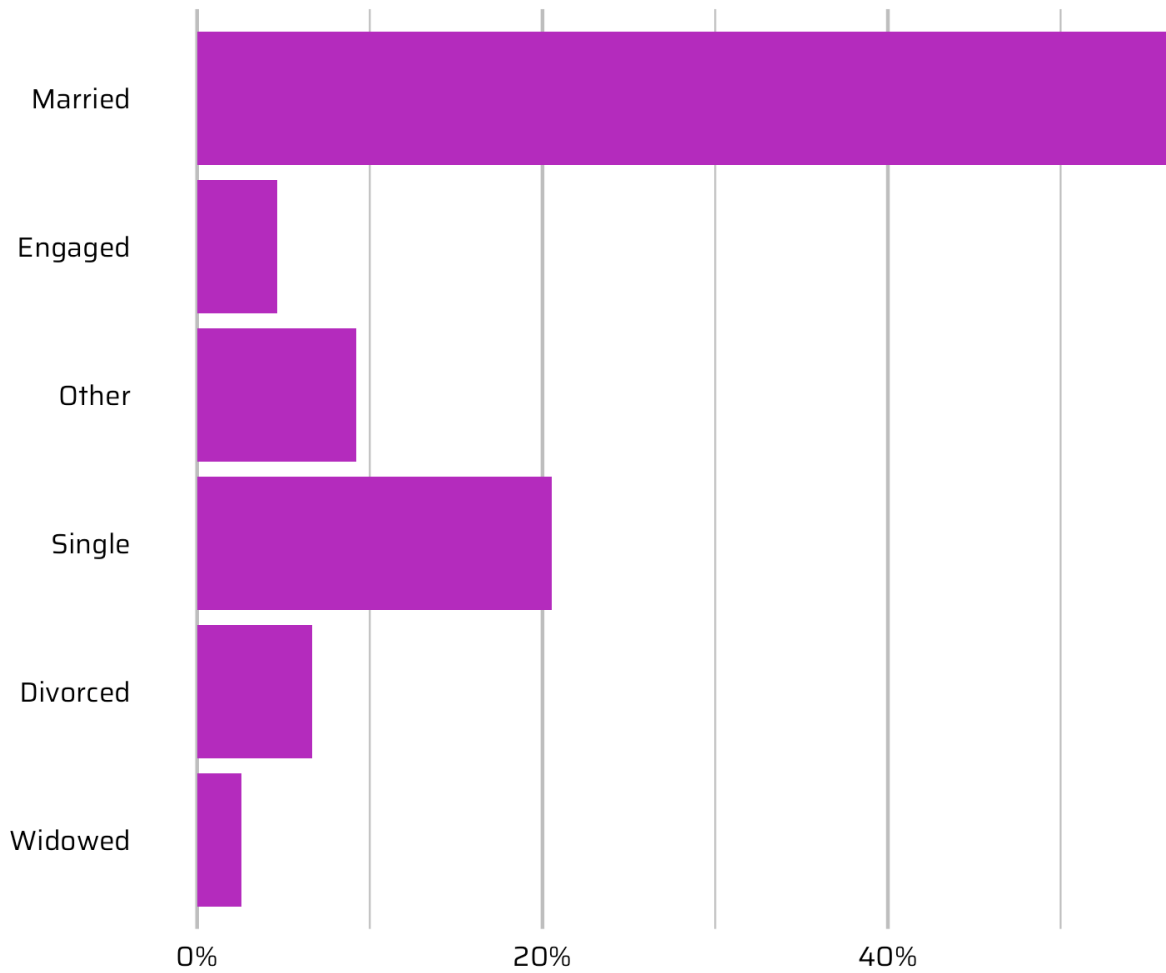


*Figure 2: Age of Respondents*

*Table 2: Age of respondents*

Age	Respondents	Percentage
<18	3	2
18-24	2	1
25-34	14	7
35-44	29	15
45-54	54	27
55-64	50	25
65-69	16	8
70+	29	15





*Figure 3: Marital status of respondents*

*Table 3: Marital status of respondents*

Marital Status	Respondents	Percentage
Married	110	56
Engaged	9	5
Other	18	9
Single	40	21
Divorced	13	7
Widowed	5	3

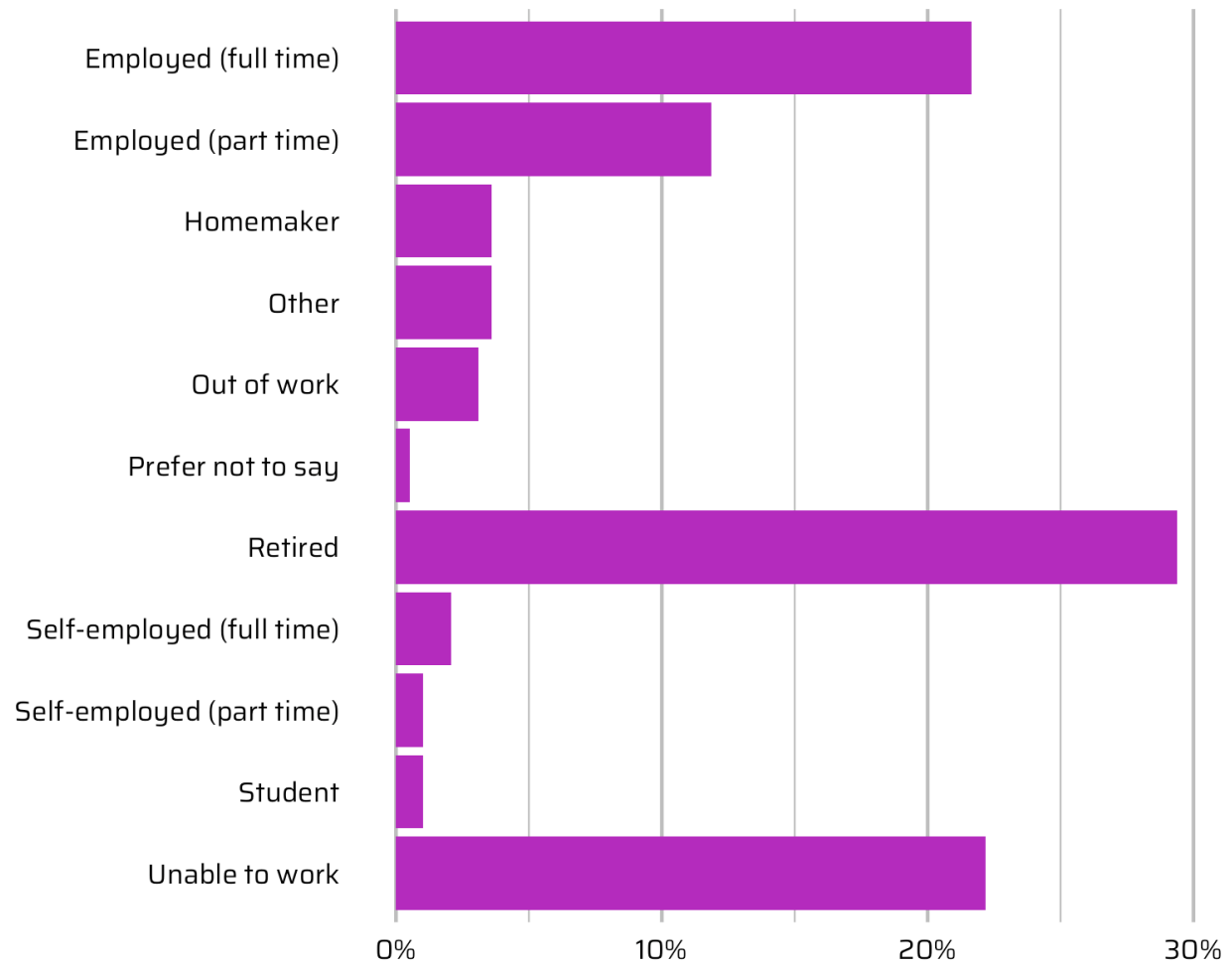


Figure 4: Employment status of respondents

Table 4: Employment status of respondents

Employment Status	Respondents	Percentage
Employed (full time)	42	22
Employed (part time)	23	12
Homemaker	7	4
Other	7	4
Out of work	6	3
Prefer not to say	1	1
Retired	57	29
Self-employed (full time)	4	2
Self-employed (part time)	2	1
Student	2	1
Unable to work	43	22

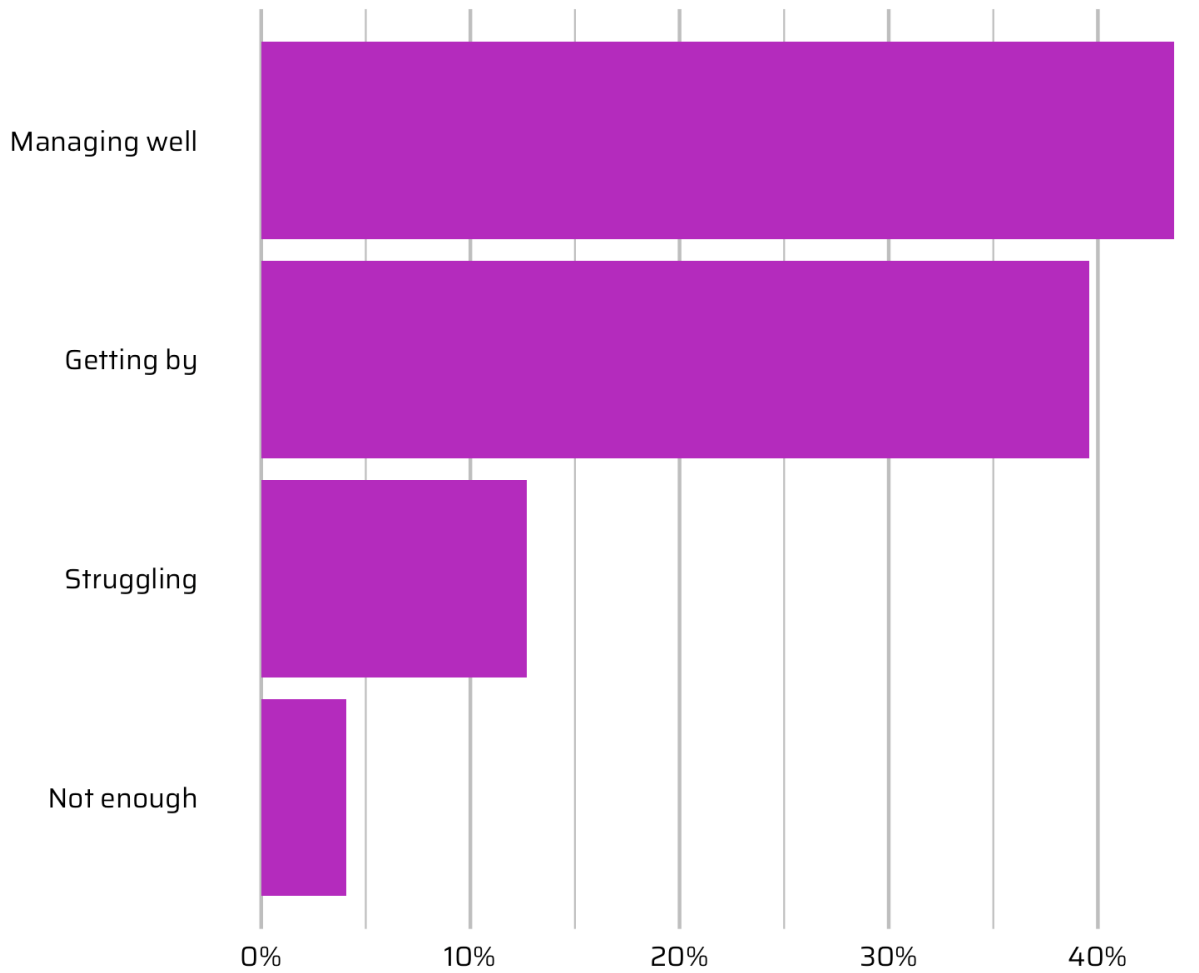


Figure 5: Financial status of respondents

Table 5: Financial status of respondents

Financial Status	Respondents	Percentage
Managing well	86	44
Getting by	78	40
Struggling	25	13
Not enough	8	4

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 74 respondents, equating to 38% of respondents, indicated that they have multiple neurological conditions.

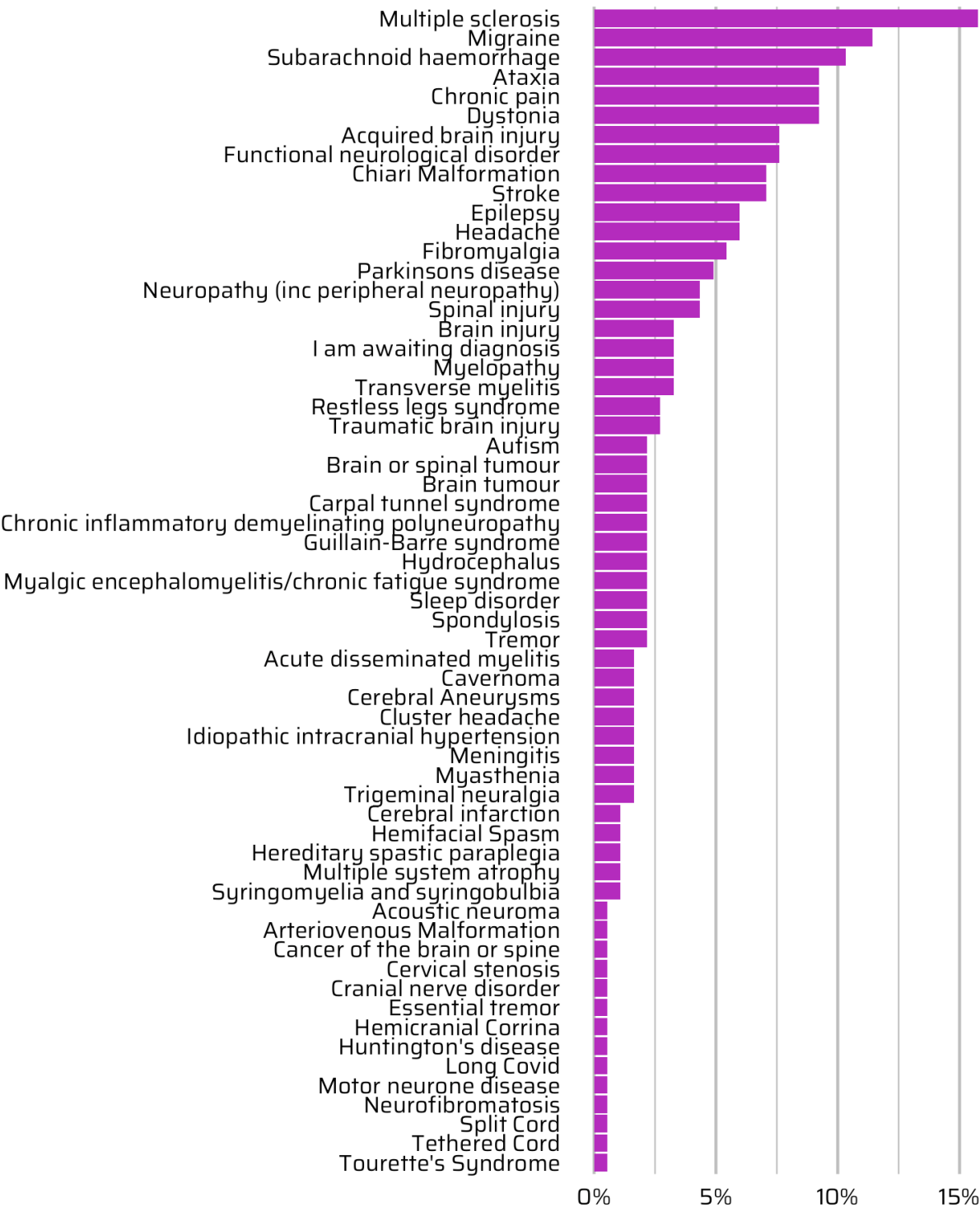


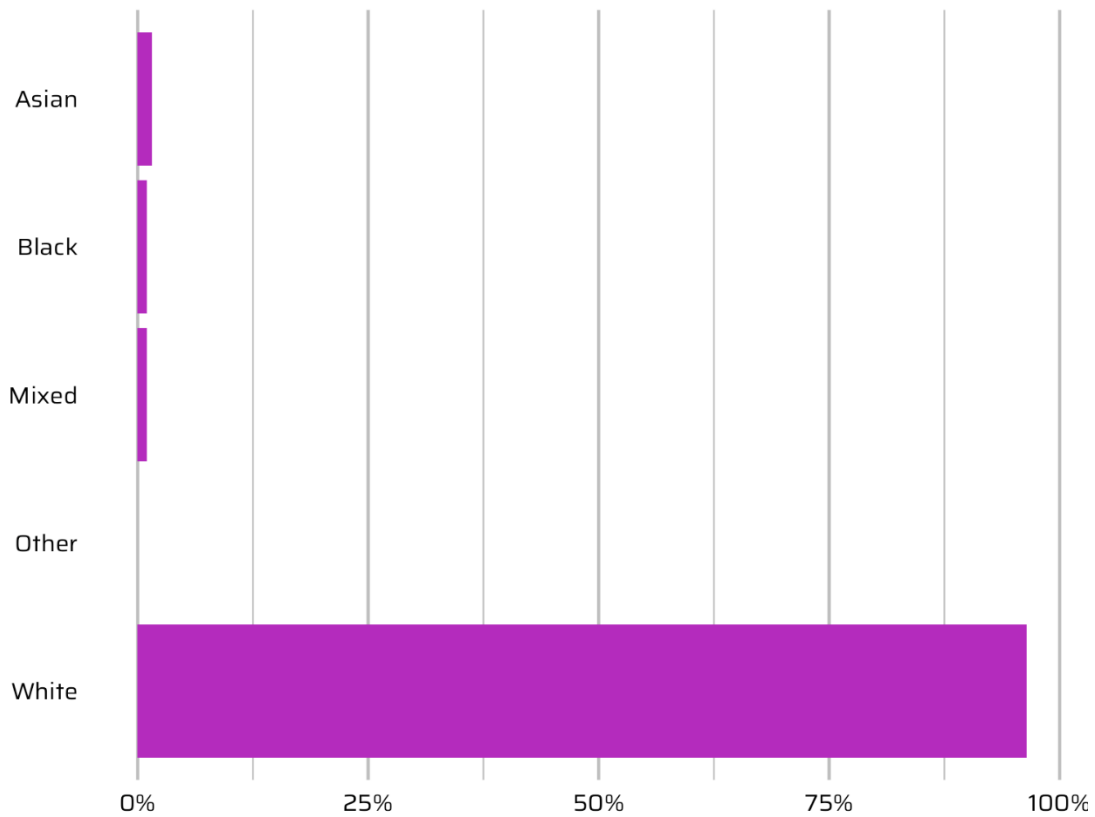
Figure 6: Neurological symptoms & conditions

Table 6: Neurological conditions & symptoms

Condition	Respondents	Percentage
-----------	-------------	------------

Multiple sclerosis	29	16
Migraine	21	11
Subarachnoid haemorrhage	19	10
Ataxia	17	9
Chronic pain	17	9
Dystonia	17	9
Acquired brain injury	14	8
Functional neurological disorder	14	8
Chiari Malformation	13	7
Stroke	13	7
Epilepsy	11	6
Headache	11	6
Fibromyalgia	10	5
Parkinsons disease	9	5
Neuropathy (inc peripheral neuropathy)	8	4
Spinal injury	8	4
Brain injury	6	3
I am awaiting diagnosis	6	3
Myelopathy	6	3
Transverse myelitis	6	3
Restless legs syndrome	5	3
Traumatic brain injury	5	3
Autism	4	2
Brain or spinal tumour	4	2
Brain tumour	4	2
Carpal tunnel syndrome	4	2
Chronic inflammatory demyelinating polyneuropathy	4	2
Guillain-Barre syndrome	4	2
Hydrocephalus	4	2
Myalgic encephalomyelitis/chronic fatigue syndrome	4	2
Sleep disorder	4	2
Spondylosis	4	2
Tremor	4	2
Acute disseminated myelitis	3	2
Cavernoma	3	2

Cerebral Aneurysms	3	2
Cluster headache	3	2
Idiopathic intracranial hypertension	3	2
Meningitis	3	2
Myasthenia	3	2
Trigeminal neuralgia	3	2
Cerebral infarction	2	1
Hemifacial Spasm	2	1
Hereditary spastic paraplegia	2	1
Multiple system atrophy	2	1
Syringomyelia and syringobulbia	2	1
Acoustic neuroma	1	1
Arteriovenous Malformation	1	1
Cancer of the brain or spine	1	1
Cervical stenosis	1	1
Cranial nerve disorder	1	1
Essential tremor	1	1
Hemicranial Corrina	1	1
Huntington's disease	1	1
Long Covid	1	1
Motor neurone disease	1	1
Neurofibromatosis	1	1
Split Cord	1	1
Tethered Cord	1	1
Tourette's Syndrome	1	1



*Figure 7: Race of respondents*

*Table 7: Race of respondents*

Race	Respondents	Percentage
Asian	3	2
Black	2	1
Mixed	2	1
Other	0	0
White	190	96

Government Guidelines

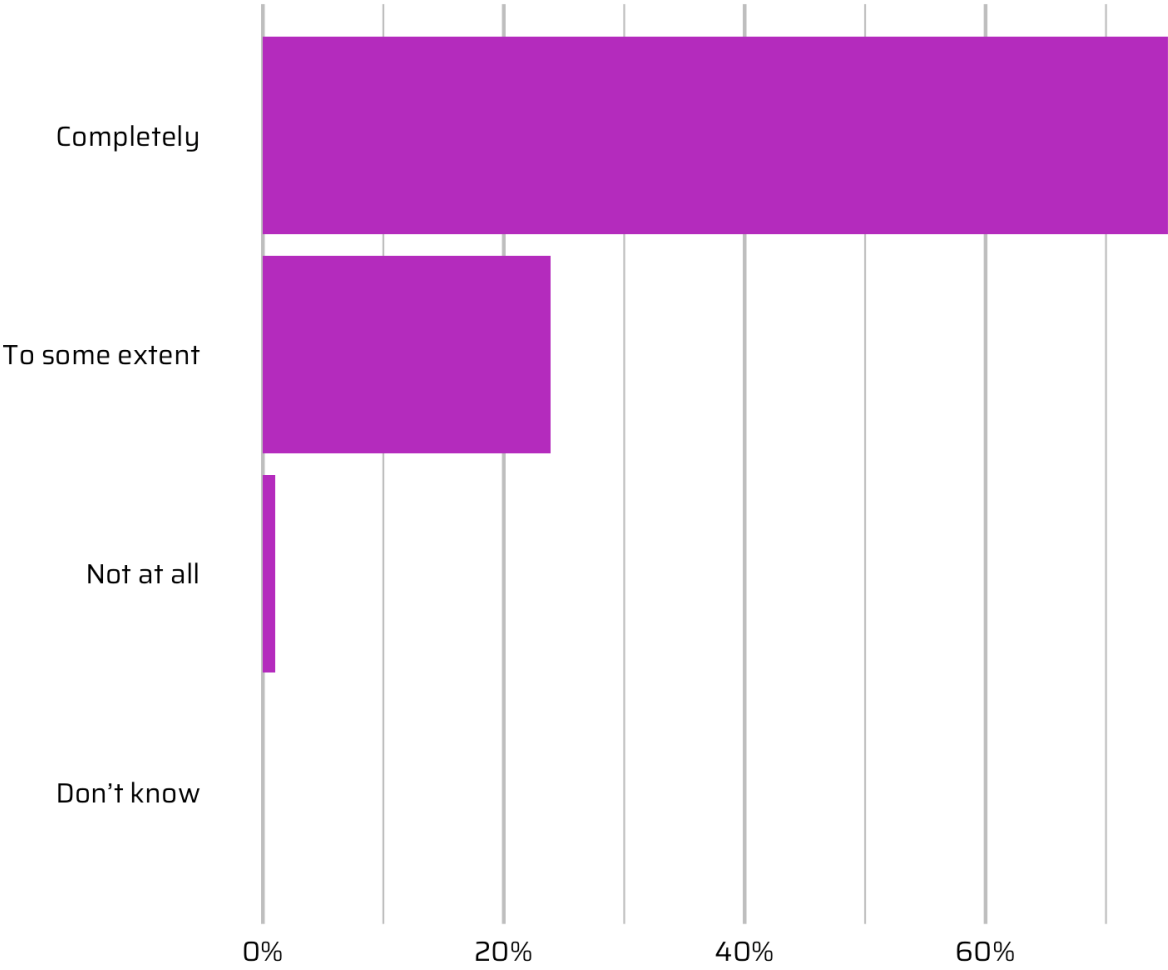


Figure 8: Extent of following COVID-19 restrictions

Table 8: Extent of following COVID-19 restrictions

Following Advice	Respondents	Percentage
Completely	148	75
To some extent	47	24
Not at all	2	1
Don't know	0	0



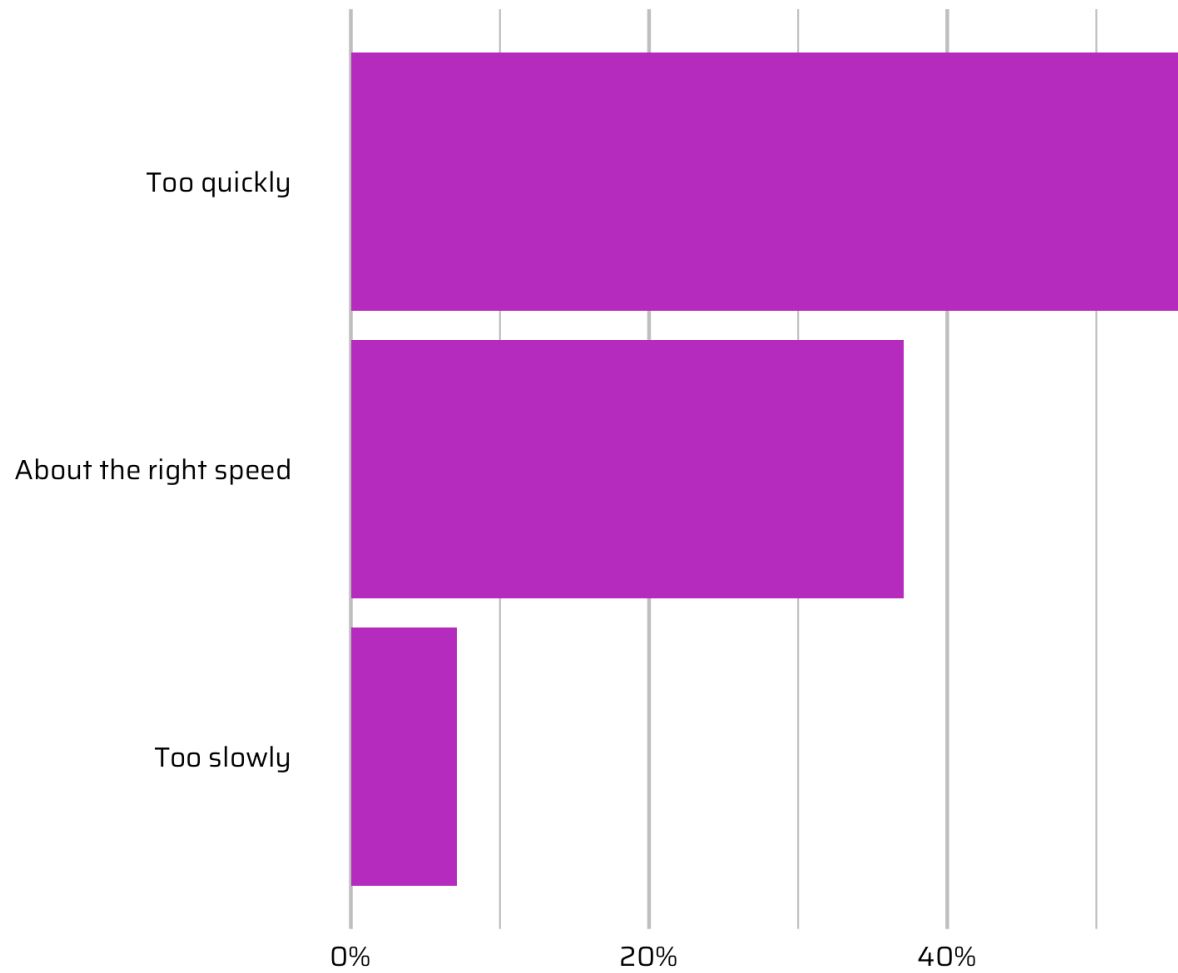


Figure 9: Evaluation of speed of lifting COVID-19 restrictions

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

Speed	Respondents	Percentage
Too quickly	110	56
About the right speed	73	37
Too slowly	14	7

Experience of care

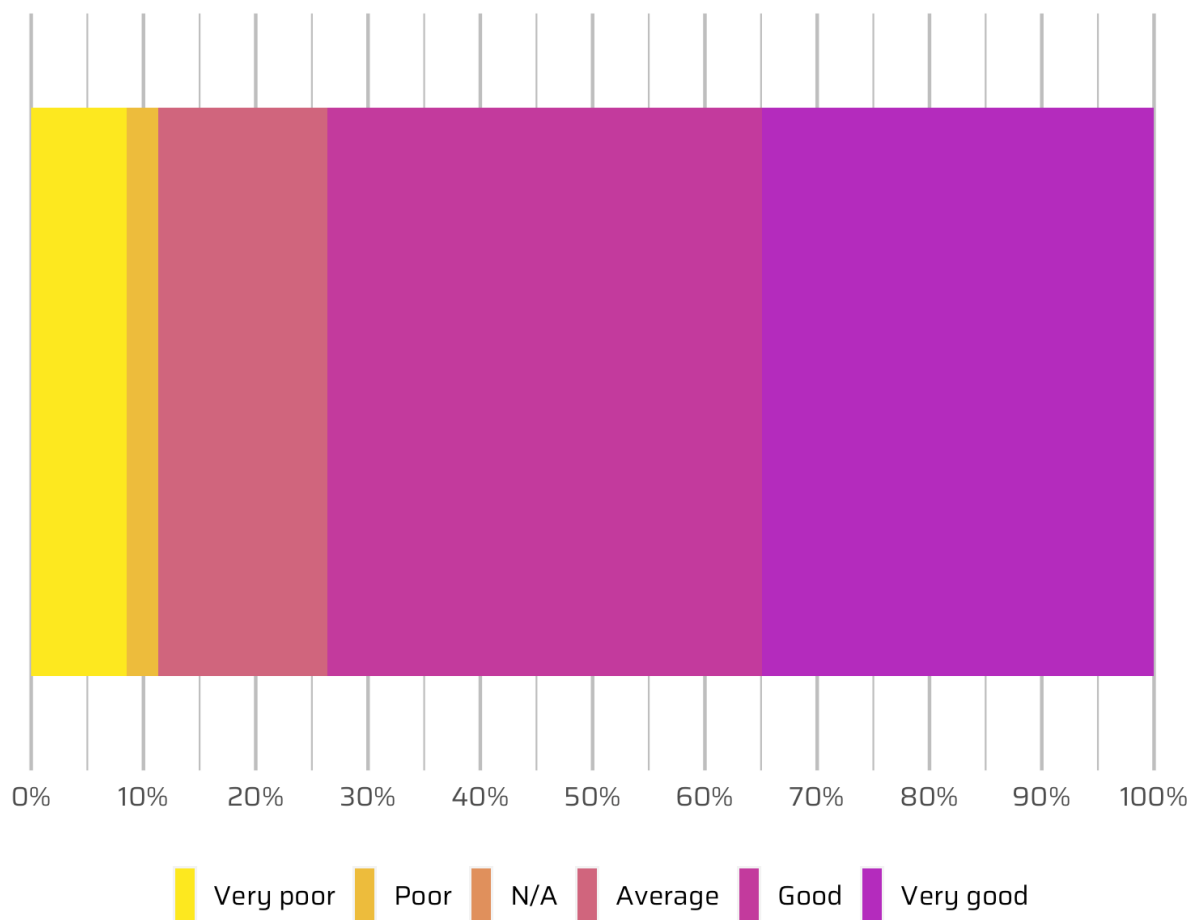


Figure 10: Overall what has your experience of care been like in the past 8 weeks?

Table 10: Number of responses to the question 'Overall, what has your experience of care been like in the last 8 weeks?'

Experience	Respondents	Percentage
Very good	37	35
Good	41	39
Average	16	15
N/A	0	0
Poor	3	3
Very poor	9	8

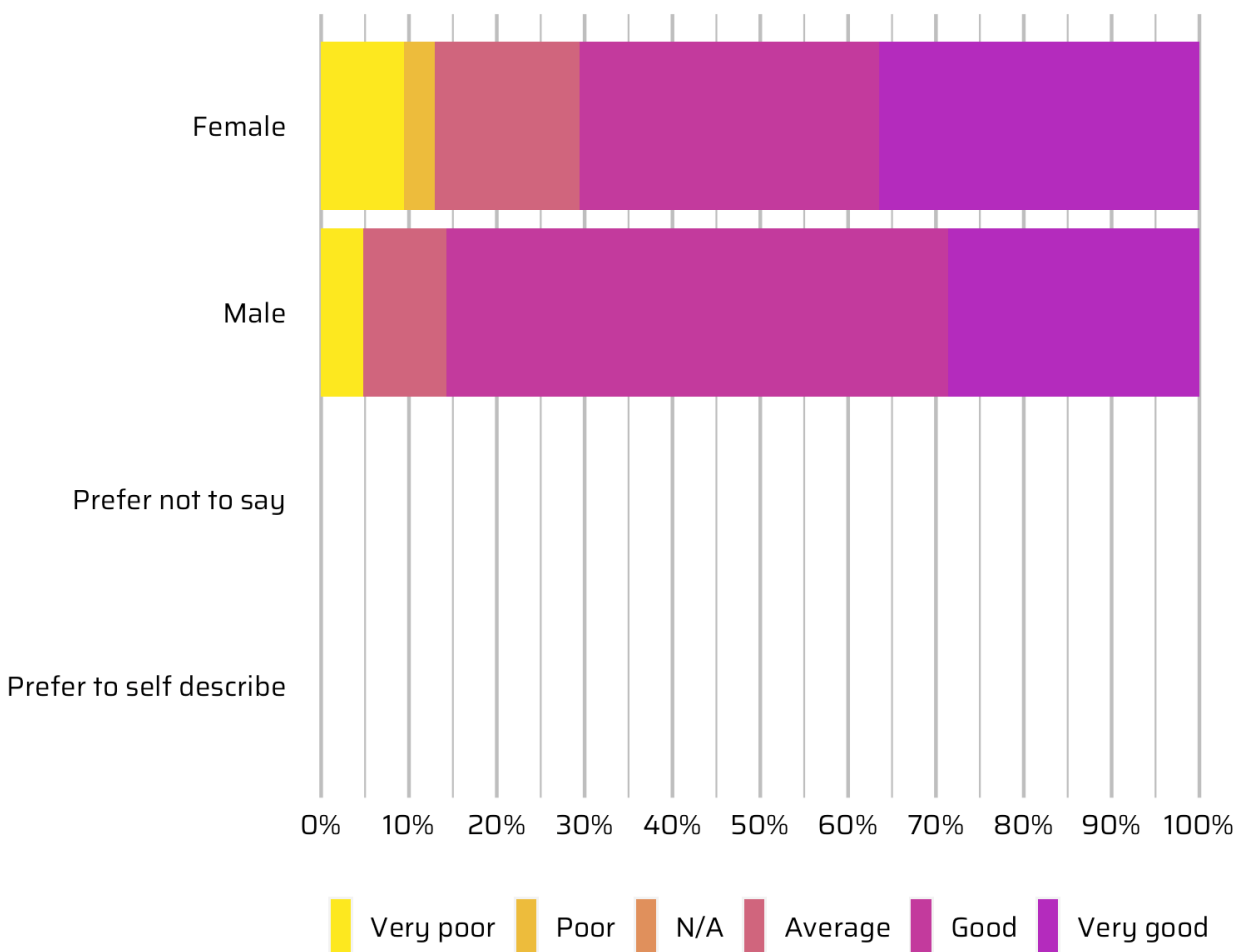


Figure 11: Experience of care by gender

Table 11: Number 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	31	36
Female	Good	29	34
Female	Average	14	16
Female	N/A	0	0
Female	Poor	3	4
Female	Very poor	8	9
Male	Very good	6	29
Male	Good	12	57
Male	Average	2	10
Male	N/A	0	0

Male	Poor	0	0
Male	Very poor	1	5
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	NaN
Prefer to self-describe	Good	0	NaN
Prefer to self-describe	Average	0	NaN
Prefer to self-describe	N/A	0	NaN
Prefer to self-describe	Poor	0	NaN
Prefer to self-describe	Very poor	0	NaN

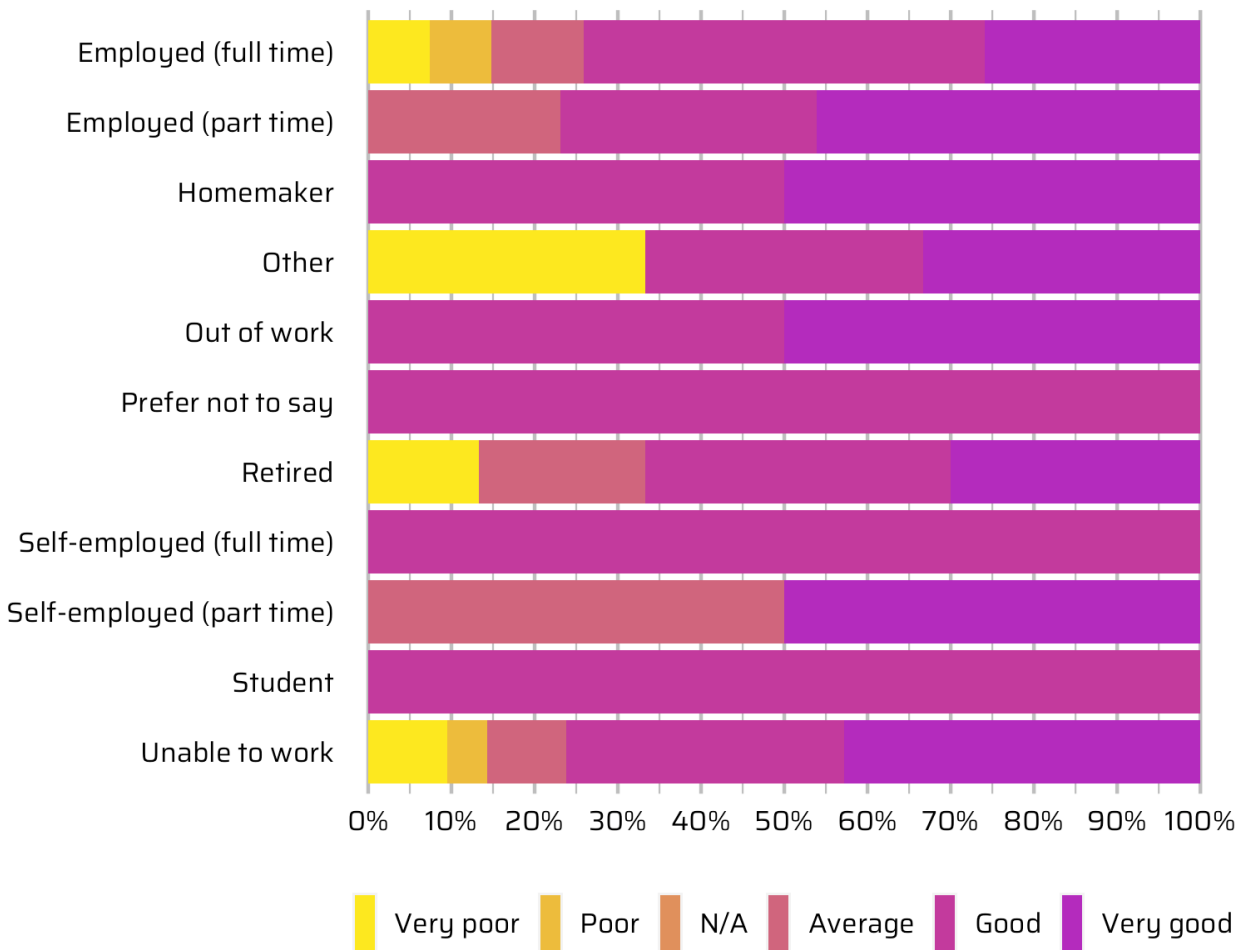


Figure 12: Experience of care by employment status.

Table 12: Number 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	7	26
Employed (full time)	Good	13	48
Employed (full time)	Average	3	11
Employed (full time)	N/A	0	0
Employed (full time)	Poor	2	7
Employed (full time)	Very poor	2	7
Employed (part time)	Very good	6	46
Employed (part time)	Good	4	31
Employed (part time)	Average	3	23
Employed (part time)	N/A	0	0

Employed (part time)	Poor	0	0
Employed (part time)	Very poor	0	0
Homemaker	Very good	1	50
Homemaker	Good	1	50
Homemaker	Average	0	0
Homemaker	N/A	0	0
Homemaker	Poor	0	0
Homemaker	Very poor	0	0
Other	Very good	1	33
Other	Good	1	33
Other	Average	0	0
Other	N/A	0	0
Other	Poor	0	0
Other	Very poor	1	33
Out of work	Very good	1	50
Out of work	Good	1	50
Out of work	Average	0	0
Out of work	N/A	0	0
Out of work	Poor	0	0
Out of work	Very poor	0	0
Prefer not to say	Very good	0	0
Prefer not to say	Good	1	100
Prefer not to say	Average	0	0
Prefer not to say	N/A	0	0
Prefer not to say	Poor	0	0
Prefer not to say	Very poor	0	0
Retired	Very good	9	30
Retired	Good	11	37
Retired	Average	6	20
Retired	N/A	0	0
Retired	Poor	0	0
Retired	Very poor	4	13
Self-employed (full time)	Very good	0	0
Self-employed (full time)	Good	1	100
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	1	50
Self-employed (part time)	Good	0	0
Self-employed (part time)	Average	1	50
Self-employed (part time)	N/A	0	0
Self-employed (part time)	Poor	0	0
Self-employed (part time)	Very poor	0	0
Student	Very good	0	0
Student	Good	1	100
Student	Average	0	0
Student	N/A	0	0
Student	Poor	0	0
Student	Very poor	0	0
Unable to work	Very good	9	43
Unable to work	Good	7	33
Unable to work	Average	2	10
Unable to work	N/A	0	0
Unable to work	Poor	1	5
Unable to work	Very poor	2	10

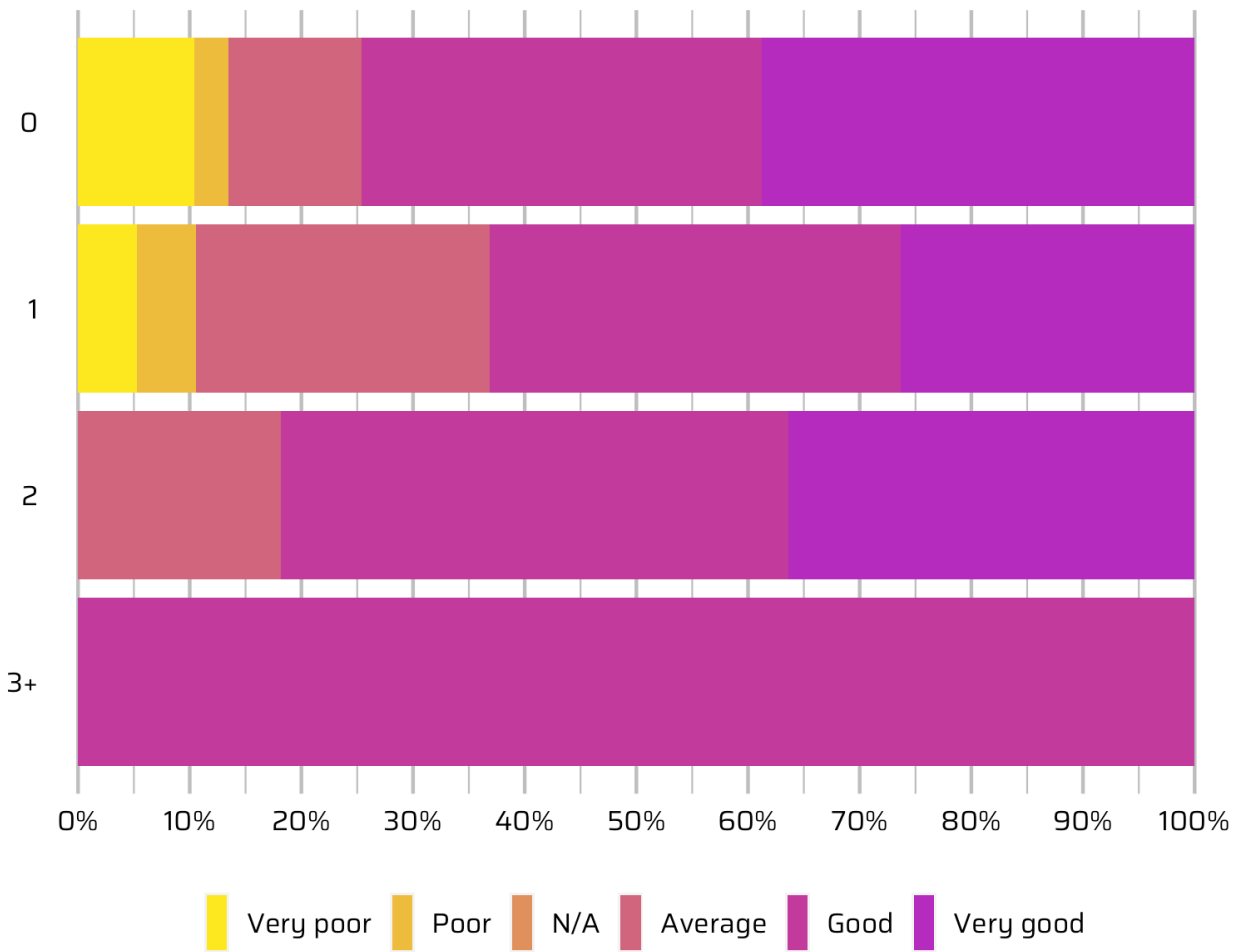


Figure 13: Experience of care by number of dependents.

Table 13: Number of responses to the question 'Overall, what has your experience of care been like in the last 8 weeks?' by number of dependents.

Dependents	Experience	Respondents	Percentage
0	Very good	26	39
0	Good	24	36
0	Average	8	12
0	N/A	0	0
0	Poor	2	3
0	Very poor	7	10
1	Very good	5	26
1	Good	7	37
1	Average	5	26
1	N/A	0	0



1	Poor	1	5
1	Very poor	1	5
2	Very good	4	36
2	Good	5	45
2	Average	2	18
2	N/A	0	0
2	Poor	0	0
2	Very poor	0	0
3+	Very good	0	0
3+	Good	5	100
3+	Average	0	0
3+	N/A	0	0
3+	Poor	0	0
3+	Very poor	0	0

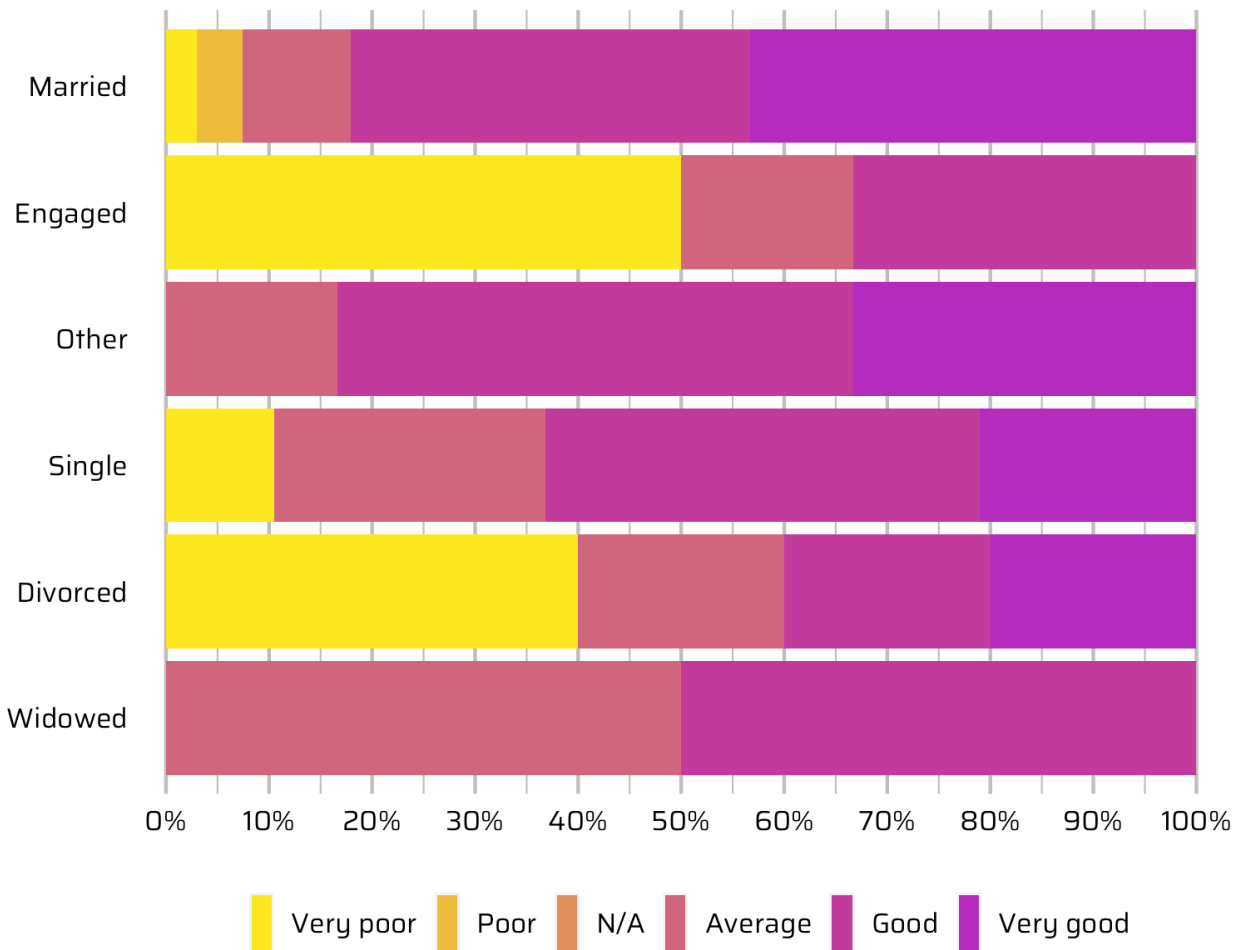


Figure 14: Experience of care by marital status.

Table 14: Number 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	29	43
Married	Good	26	39
Married	Average	7	10
Married	N/A	0	0
Married	Poor	3	4
Married	Very poor	2	3
Engaged	Very good	0	0
Engaged	Good	2	33
Engaged	Average	1	17
Engaged	N/A	0	0

Engaged	Poor	0	0
Engaged	Very poor	3	50
Other	Very good	2	33
Other	Good	3	50
Other	Average	1	17
Other	N/A	0	0
Other	Poor	0	0
Other	Very poor	0	0
Single	Very good	4	21
Single	Good	8	42
Single	Average	5	26
Single	N/A	0	0
Single	Poor	0	0
Single	Very poor	2	11
Divorced	Very good	1	20
Divorced	Good	1	20
Divorced	Average	1	20
Divorced	N/A	0	0
Divorced	Poor	0	0
Divorced	Very poor	2	40
Widowed	Very good	0	0
Widowed	Good	1	50
Widowed	Average	1	50
Widowed	N/A	0	0
Widowed	Poor	0	0
Widowed	Very poor	0	0

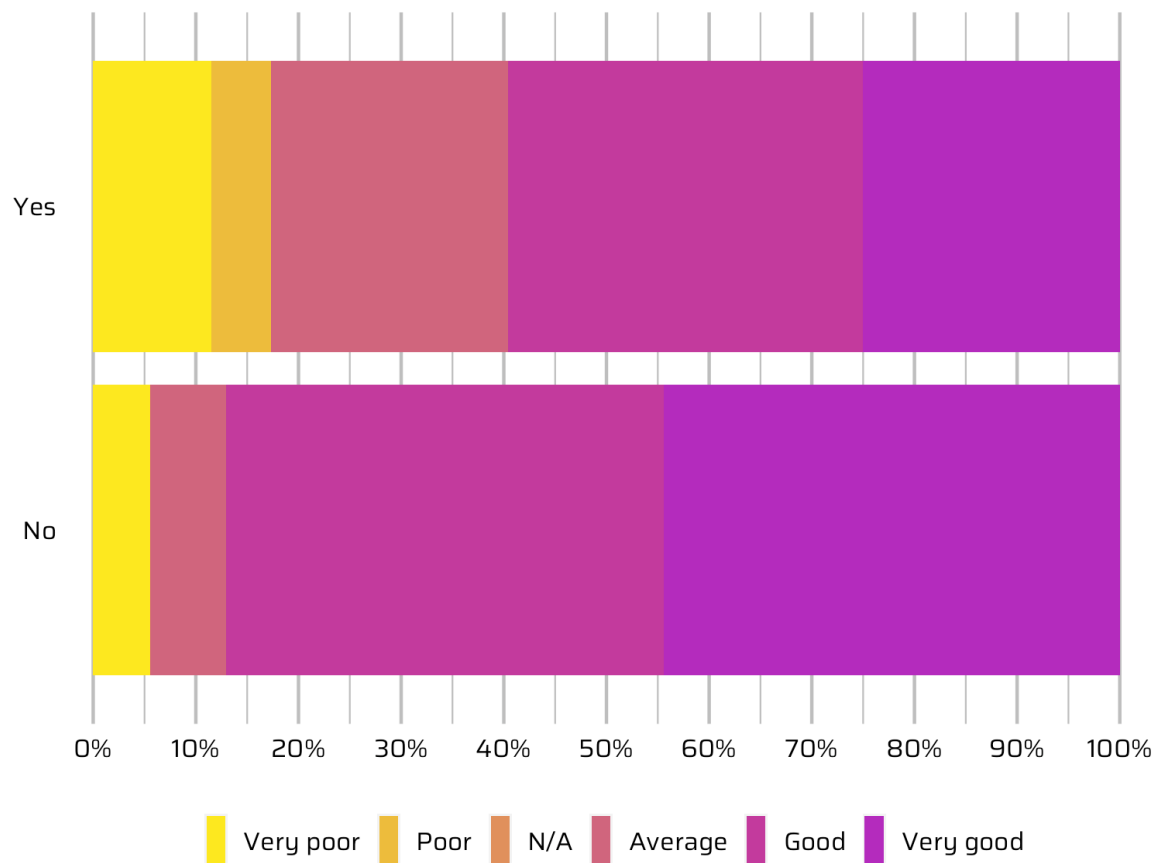


Figure 15: Experience of care and mental wellbeing.

Table 15: Number of responses to the question 'Overall, what has your experience of care been like in the last 8 weeks? by feelings of being anxious of hopeless.

Anxious or Hopeless	Experience	Respondents	Percentage
Yes	Very good	13	25
Yes	Good	18	35
Yes	Average	12	23
Yes	N/A	0	0
Yes	Poor	3	6
Yes	Very poor	6	12
No	Very good	24	44
No	Good	23	43
No	Average	4	7
No	N/A	0	0
No	Poor	0	0
No	Very poor	3	6

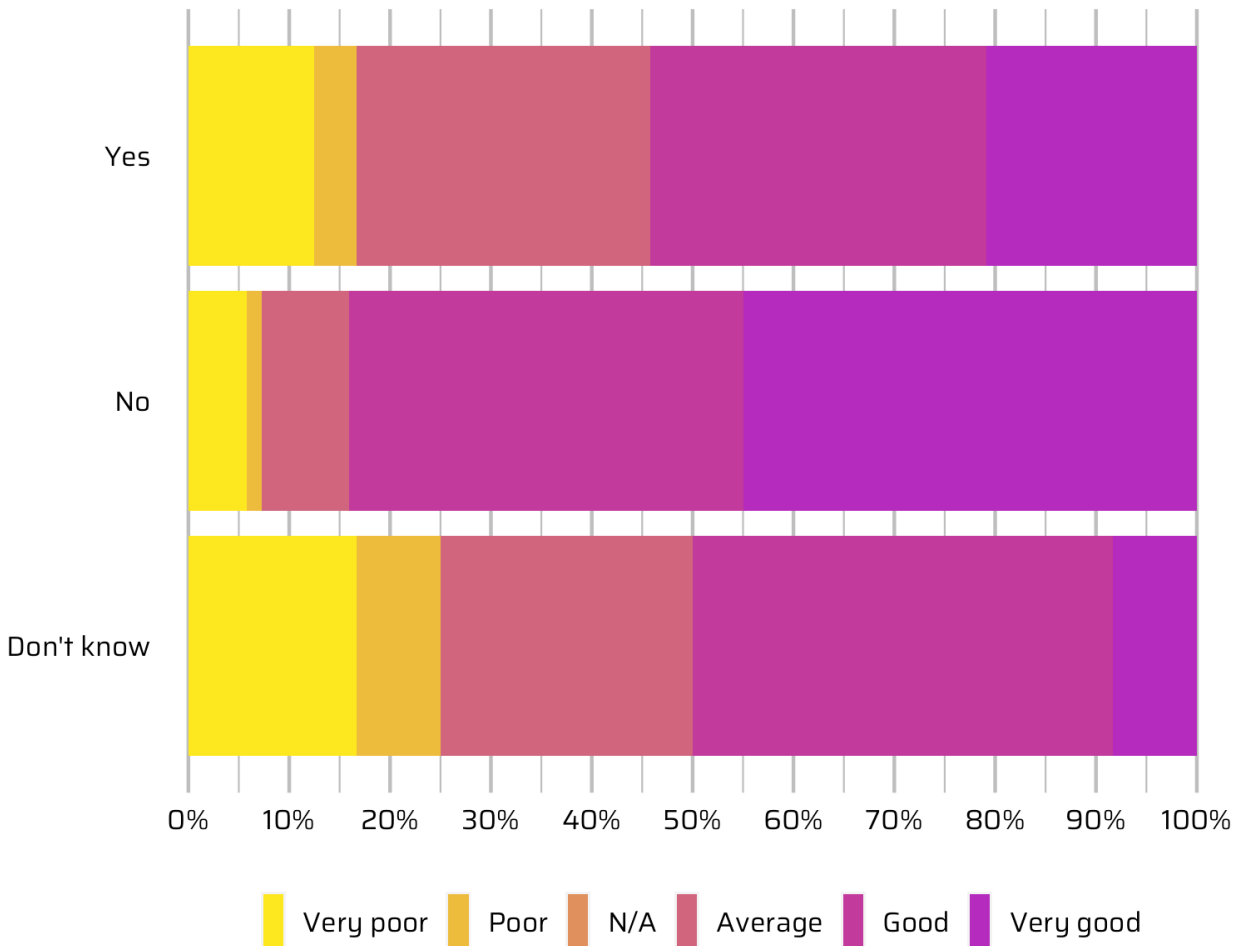


Figure 16: Experience of care by delays to care.

Table 16: Number of responses to the question 'Overall, what has your experience of care been like in the last 8 weeks?' by delays to care.

Delay	Experience	Respondents	Percentage
Yes	Very good	5	21
Yes	Good	8	33
Yes	Average	7	29
Yes	N/A	0	0
Yes	Poor	1	4
Yes	Very poor	3	12
No	Very good	31	45
No	Good	27	39
No	Average	6	9
No	N/A	0	0
No	Poor	1	1
No	Very poor	4	6

Don't know	Very good	1	8
Don't know	Good	5	42
Don't know	Average	3	25
Don't know	N/A	0	0
Don't know	Poor	1	8
Don't know	Very poor	2	17

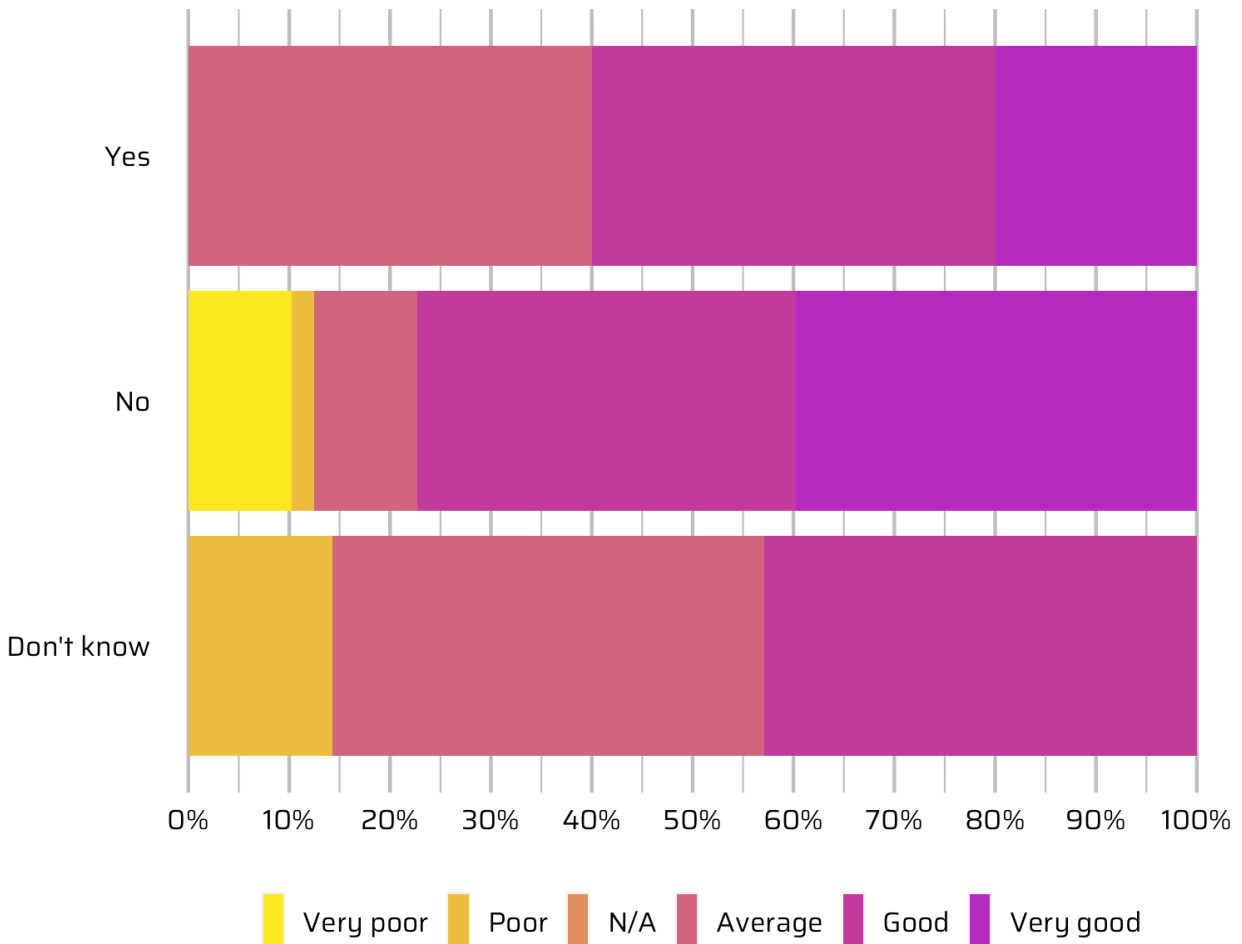


Figure 17: Experience of care by cancellations of care.

Table 17: Number of responses to the question 'Overall, what has your experience of care been like in the last 8 weeks?' by cancellations of care.

Cancellation	Experience	Respondents	Percentage
Yes	Very good	2	20
Yes	Good	4	40
Yes	Average	4	40
Yes	N/A	0	0
Yes	Poor	0	0
Yes	Very poor	0	0
No	Very good	35	40
No	Good	33	38
No	Average	9	10
No	N/A	0	0
No	Poor	2	2
No	Very poor	9	10

Don't know	Very good	0	0
Don't know	Good	3	43
Don't know	Average	3	43
Don't know	N/A	0	0
Don't know	Poor	1	14
Don't know	Very poor	0	0



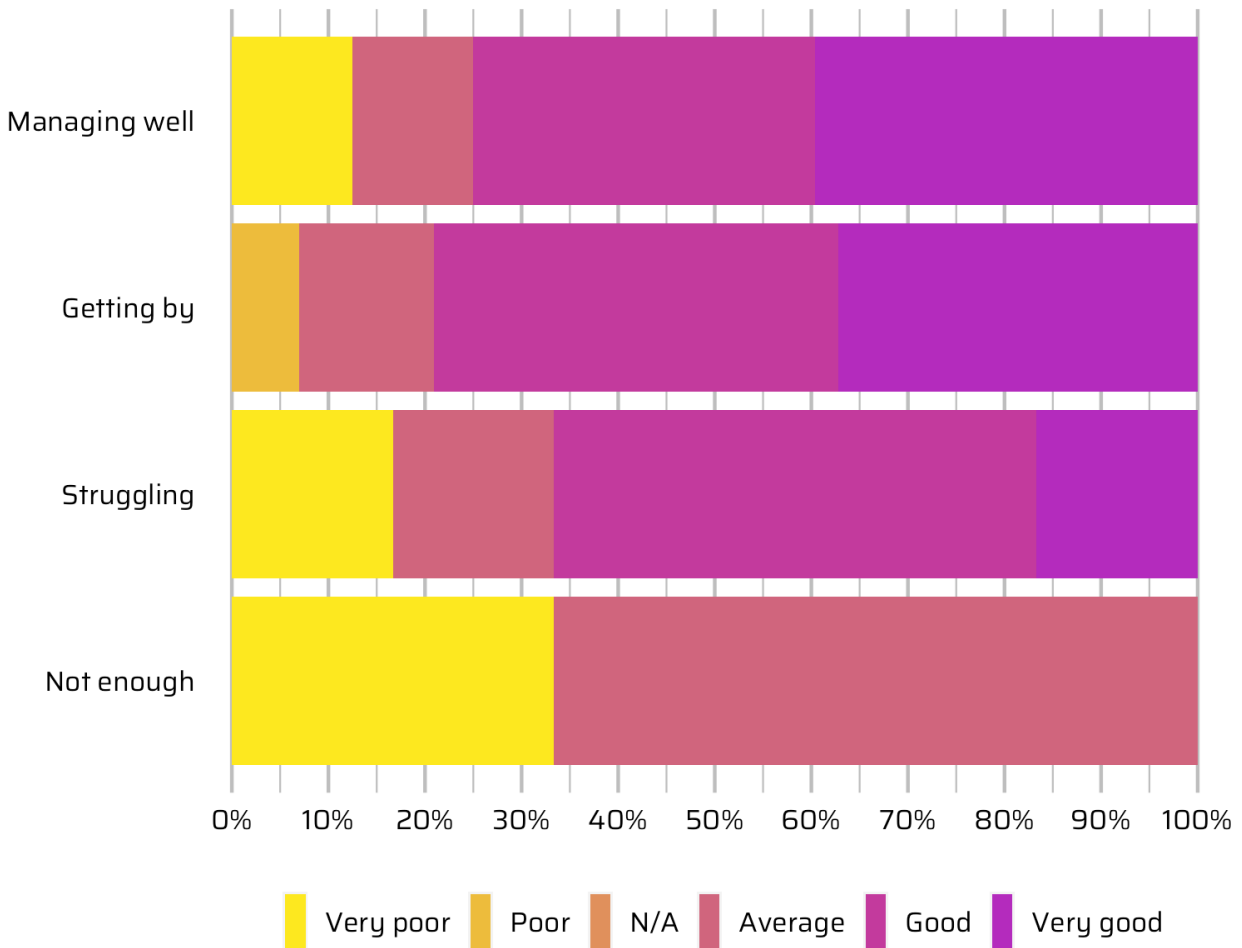


Figure 18: Experience of care by financial status.

Table 18: Number of responses to the question 'Overall, what has your experience of care been like in the last 8 weeks?' by financial status.

Financial Status	Experience	Respondents	Percentage
Managing well	Very good	19	40
Managing well	Good	17	35
Managing well	Average	6	12
Managing well	N/A	0	0
Managing well	Poor	0	0
Managing well	Very poor	6	12
Getting by	Very good	16	37
Getting by	Good	18	42
Getting by	Average	6	14
Getting by	N/A	0	0
Getting by	Poor	3	7
Getting by	Very poor	0	0

Struggling	Very good	2	17
Struggling	Good	6	50
Struggling	Average	2	17
Struggling	N/A	0	0
Struggling	Poor	0	0
Struggling	Very poor	2	17
Not enough	Very good	0	0
Not enough	Good	0	0
Not enough	Average	2	67
Not enough	N/A	0	0
Not enough	Poor	0	0
Not enough	Very poor	1	33

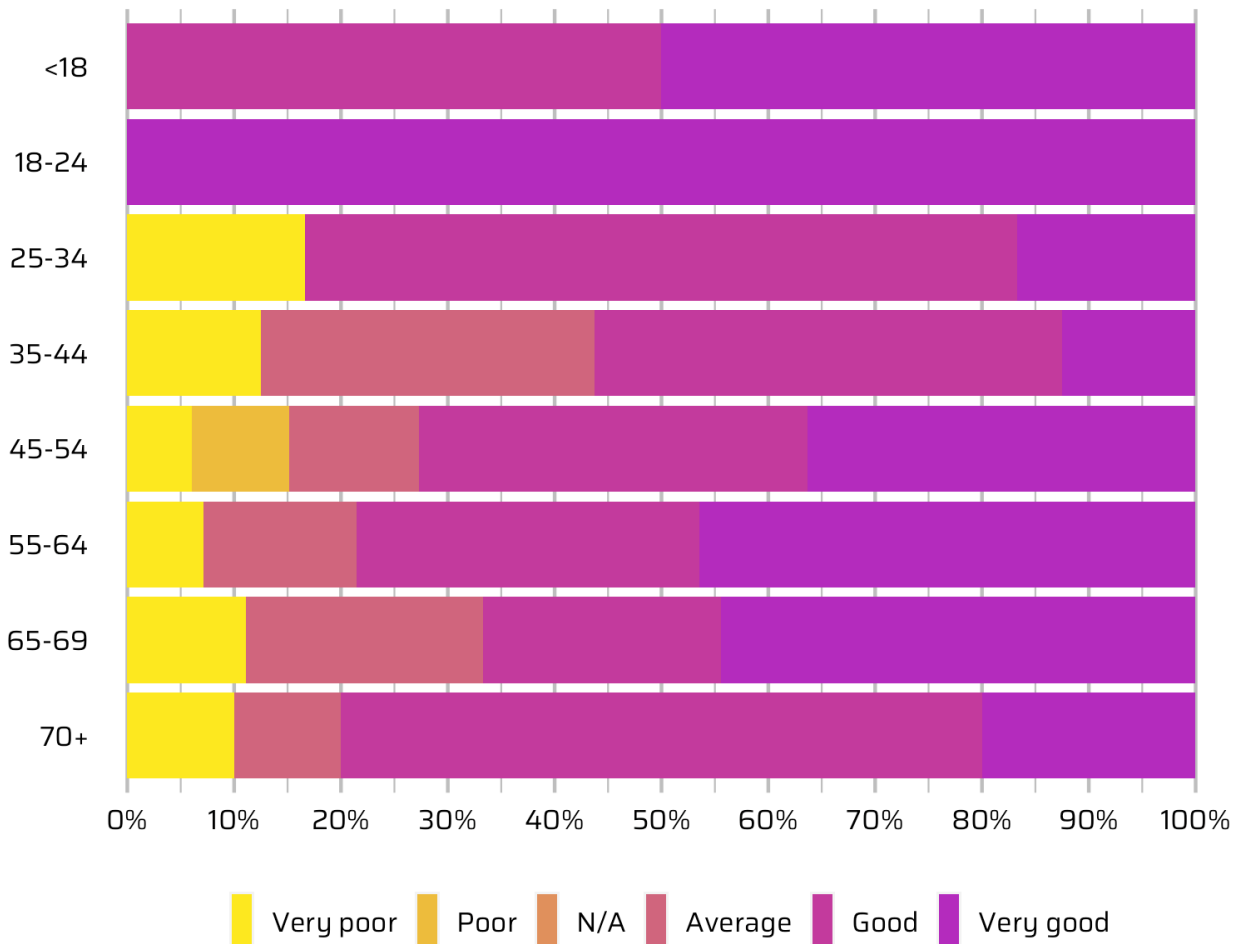


Figure 19: Experience of care by age group.

Table 19: Number 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	1	50
<18	Good	1	50
<18	Average	0	0
<18	N/A	0	0
<18	Poor	0	0
<18	Very poor	0	0
18-24	Very good	2	100
18-24	Good	0	0

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	1	17
25-34	Good	4	67
25-34	Average	0	0
25-34	N/A	0	0
25-34	Poor	0	0
25-34	Very poor	1	17
35-44	Very good	2	12
35-44	Good	7	44
35-44	Average	5	31
35-44	N/A	0	0
35-44	Poor	0	0
35-44	Very poor	2	12
45-54	Very good	12	36
45-54	Good	12	36
45-54	Average	4	12
45-54	N/A	0	0
45-54	Poor	3	9
45-54	Very poor	2	6
55-64	Very good	13	46
55-64	Good	9	32
55-64	Average	4	14
55-64	N/A	0	0

55-64	Poor	0	0
55-64	Very poor	2	7
65-69	Very good	4	44
65-69	Good	2	22
65-69	Average	2	22
65-69	N/A	0	0
65-69	Poor	0	0
65-69	Very poor	1	11
70+	Very good	2	20
70+	Good	6	60
70+	Average	1	10
70+	N/A	0	0
70+	Poor	0	0
70+	Very poor	1	10

Access to mental health support

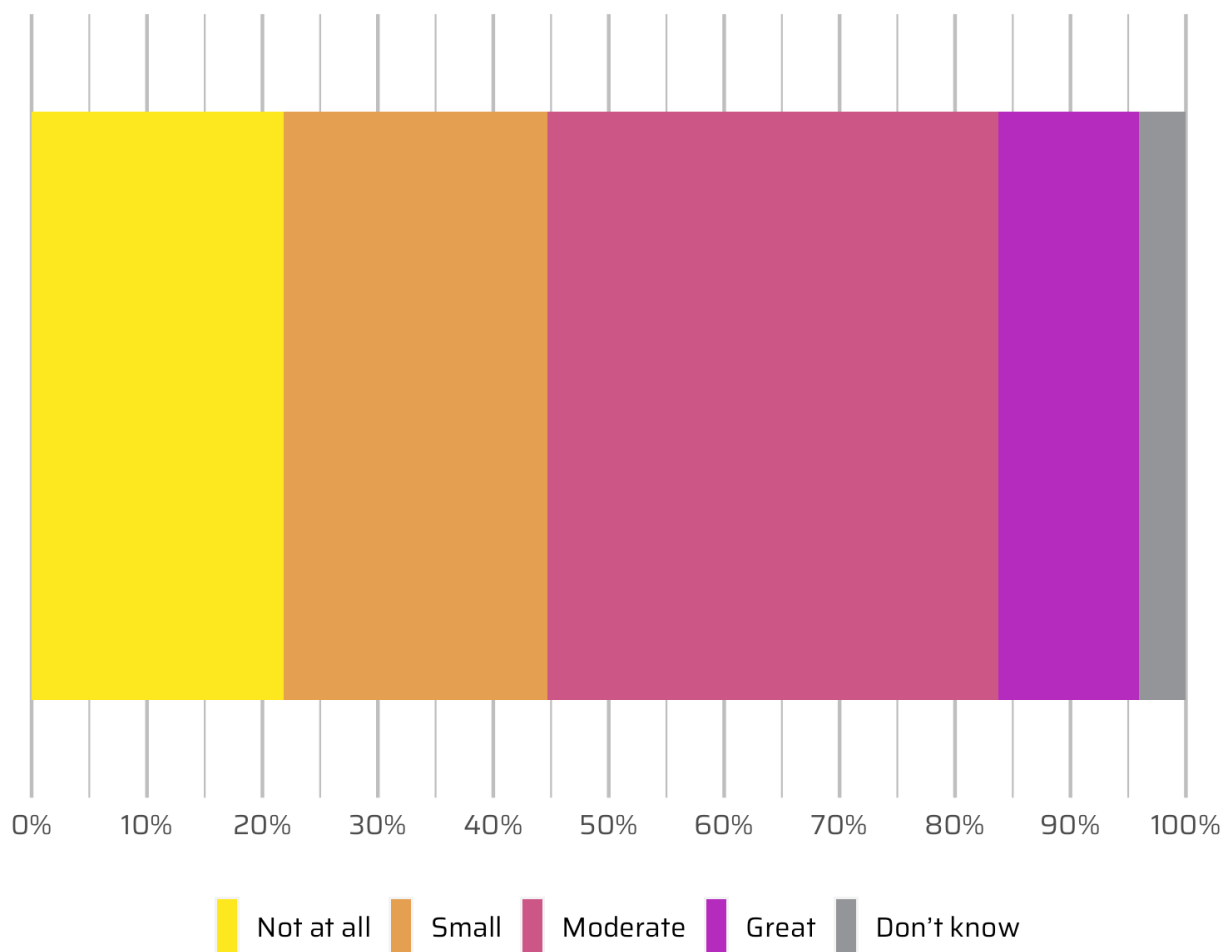


Figure 20: To what extent are your mental health needs being met?

Table 20: Number and type of responses to the question 'To what extent do you feel your mental health needs are being met?'

Extent	Respondents	Percentage
Great	24	12
Moderate	77	39
Small	45	23
Not at all	43	22
Don't know	8	4

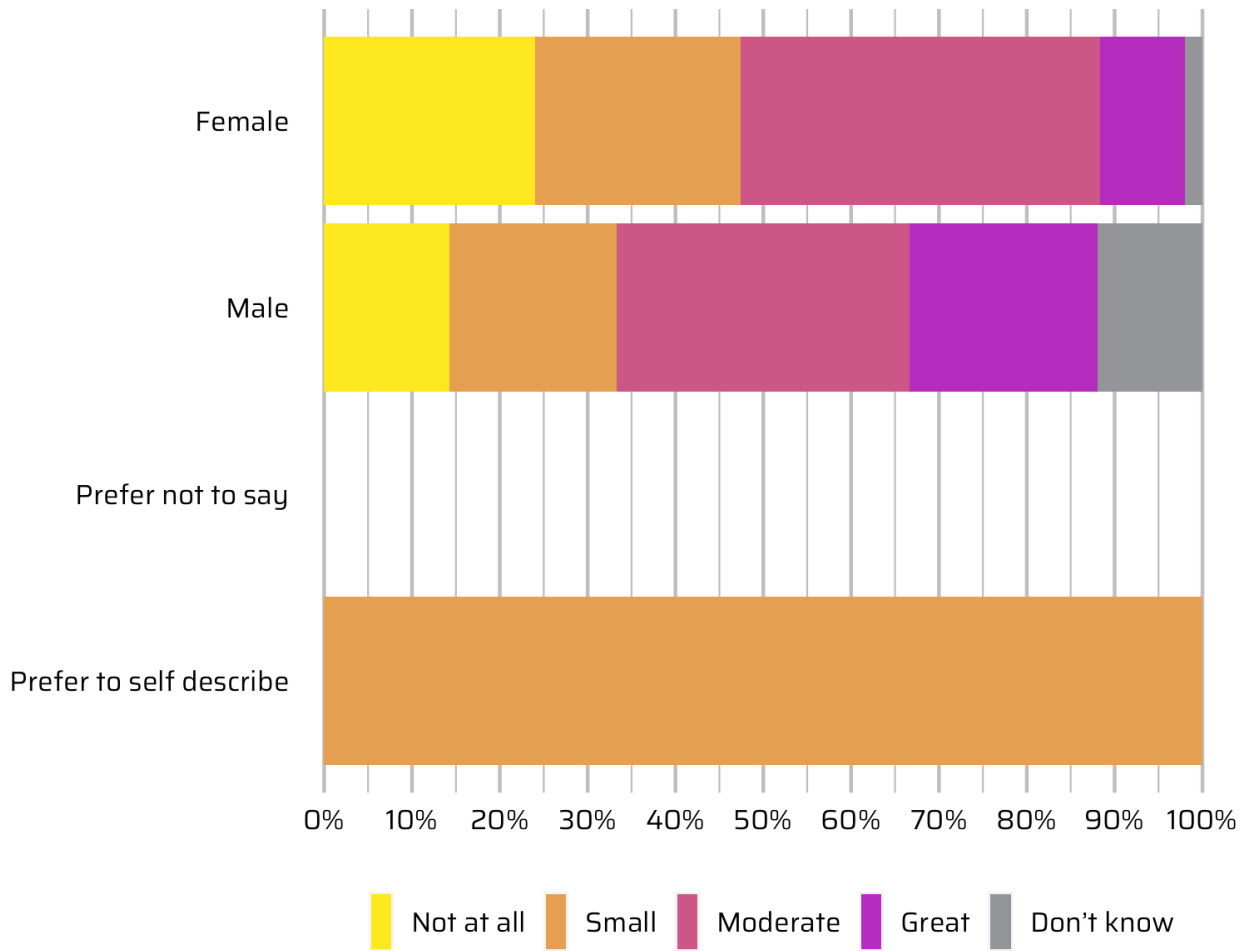


Figure 21: To what extent are your mental health needs being met by gender.

Table 21: Number 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	15	10
Female	Moderate	63	41
Female	Small	36	23
Female	Not at all	37	24
Female	Don't know	3	2
Male	Great	9	21
Male	Moderate	14	33
Male	Small	8	19
Male	Not at all	6	14
Male	Don't know	5	12

Prefer not to say	Great	0	NaN
Prefer not to say	Moderate	0	NaN
Prefer not to say	Small	0	NaN
Prefer not to say	Not at all	0	NaN
Prefer not to say	Don't know	0	NaN
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



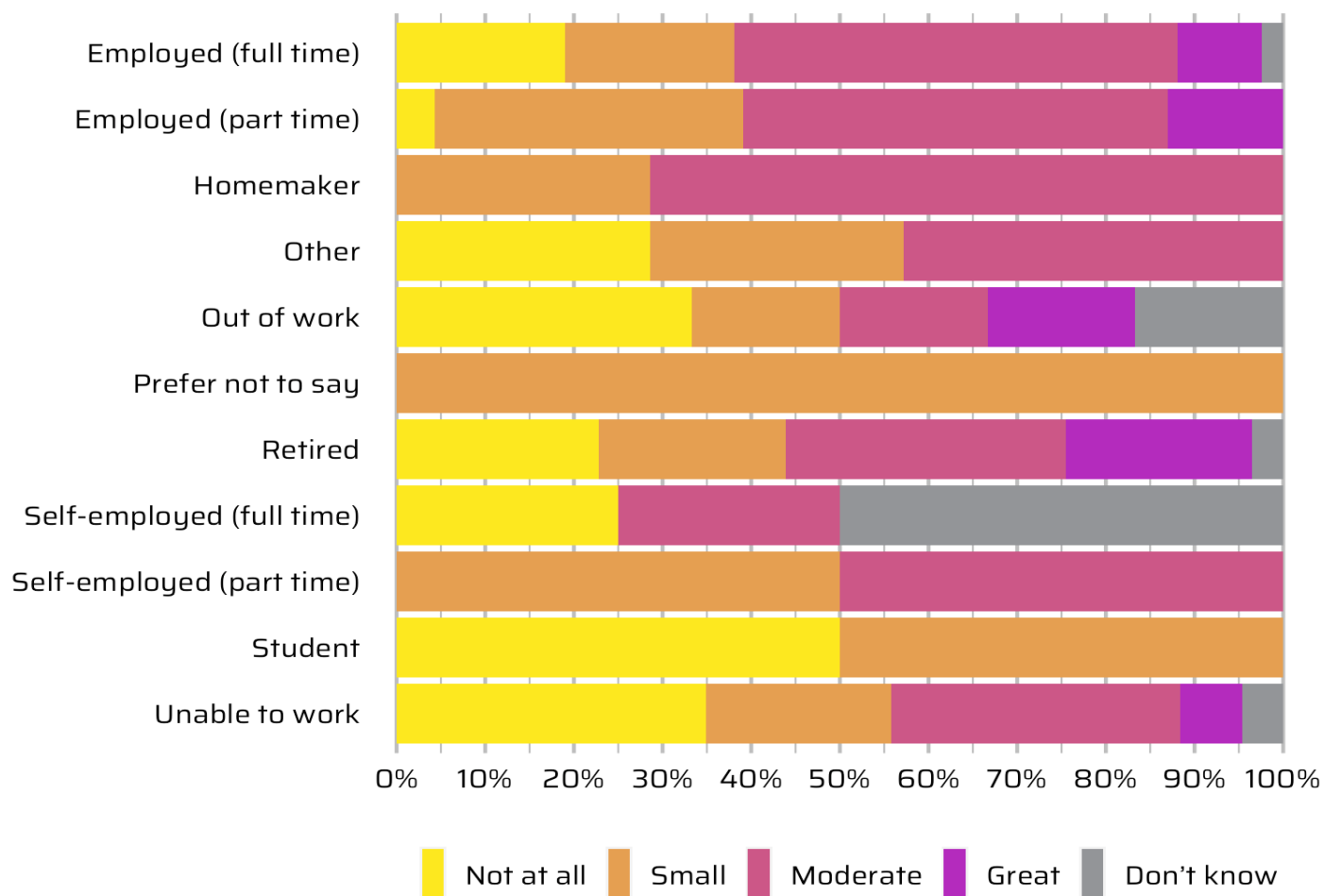


Figure 22: Mental health needs met by employment status.

Table 22: Number 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	4	10
Employed (full time)	Moderate	21	50
Employed (full time)	Small	8	19
Employed (full time)	Not at all	8	19
Employed (full time)	Don't know	1	2
Employed (part time)	Great	3	13
Employed (part time)	Moderate	11	48
Employed (part time)	Small	8	35
Employed (part time)	Not at all	1	4

Employed (part time)	Don't know	0	0
Homemaker	Great	0	0
Homemaker	Moderate	5	71
Homemaker	Small	2	29
Homemaker	Not at all	0	0
Homemaker	Don't know	0	0
Other	Great	0	0
Other	Moderate	3	43
Other	Small	2	29
Other	Not at all	2	29
Other	Don't know	0	0
Out of work	Great	1	17
Out of work	Moderate	1	17
Out of work	Small	1	17
Out of work	Not at all	2	33
Out of work	Don't know	1	17
Prefer not to say	Great	0	0
Prefer not to say	Moderate	0	0
Prefer not to say	Small	1	100
Prefer not to say	Not at all	0	0
Prefer not to say	Don't know	0	0
Retired	Great	12	21
Retired	Moderate	18	32
Retired	Small	12	21
Retired	Not at all	13	23
Retired	Don't know	2	4
Self-employed (full time)	Great	0	0
Self-employed (full time)	Moderate	1	25
Self-employed (full time)	Small	0	0
Self-employed (full time)	Not at all	1	25

Self-employed (full time)	Don't know	2	50
Self-employed (part time)	Great	0	0
Self-employed (part time)	Moderate	1	50
Self-employed (part time)	Small	1	50
Self-employed (part time)	Not at all	0	0
Self-employed (part time)	Don't know	0	0
Student	Great	0	0
Student	Moderate	0	0
Student	Small	1	50
Student	Not at all	1	50
Student	Don't know	0	0
Unable to work	Great	3	7
Unable to work	Moderate	14	33
Unable to work	Small	9	21
Unable to work	Not at all	15	35
Unable to work	Don't know	2	5

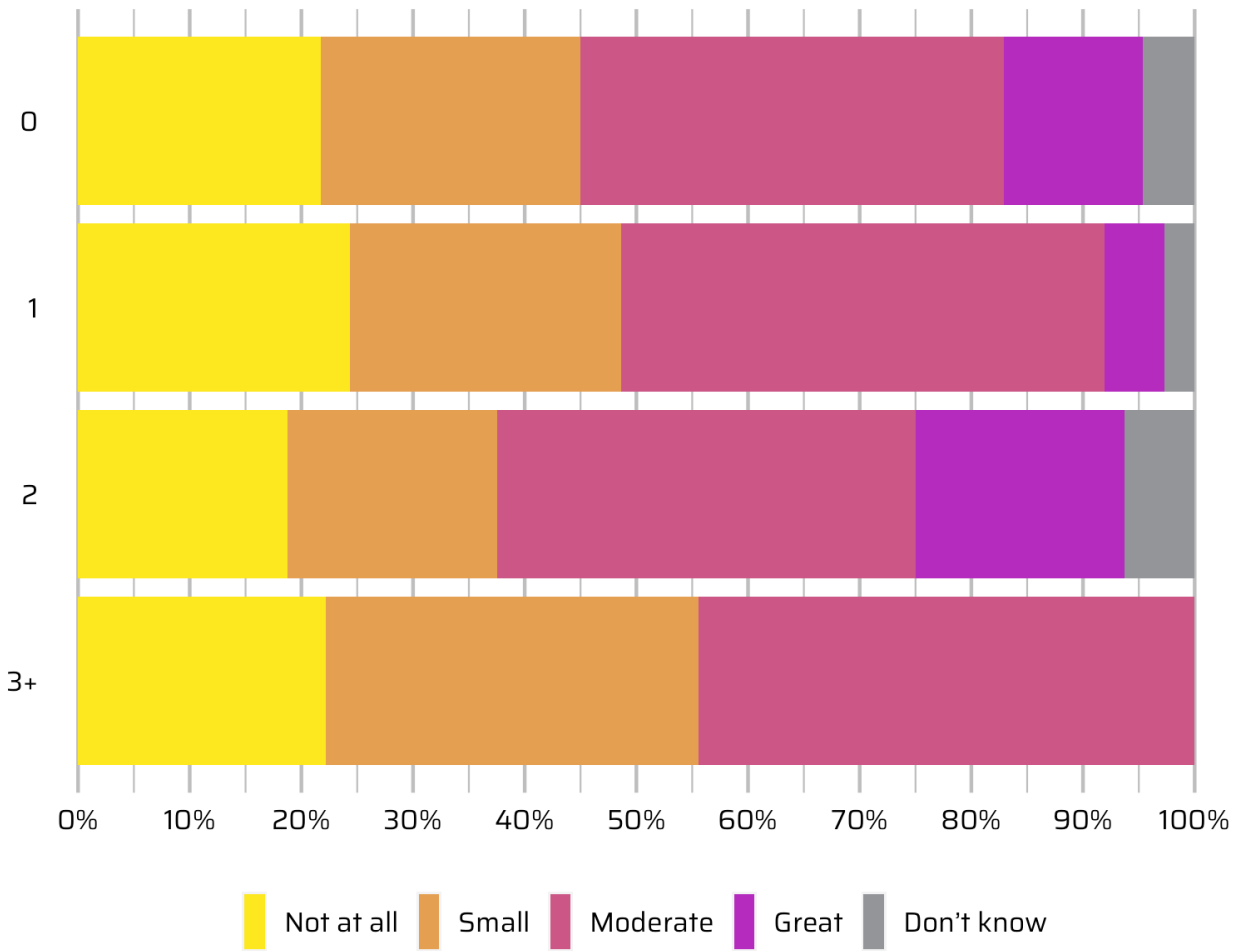


Figure 23: Number of dependents by mental health needs being met.

Table 23 Number 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	16	12
0	Moderate	49	38
0	Small	30	23
0	Not at all	28	22
0	Don't know	6	5
1	Great	2	5
1	Moderate	16	43
1	Small	9	24
1	Not at all	9	24
1	Don't know	1	3
2	Great	3	19
2	Moderate	6	38

2	Small	3	19
2	Not at all	3	19
2	Don't know	1	6
3+	Great	0	0
3+	Moderate	4	44
3+	Small	3	33
3+	Not at all	2	22
3+	Don't know	0	0

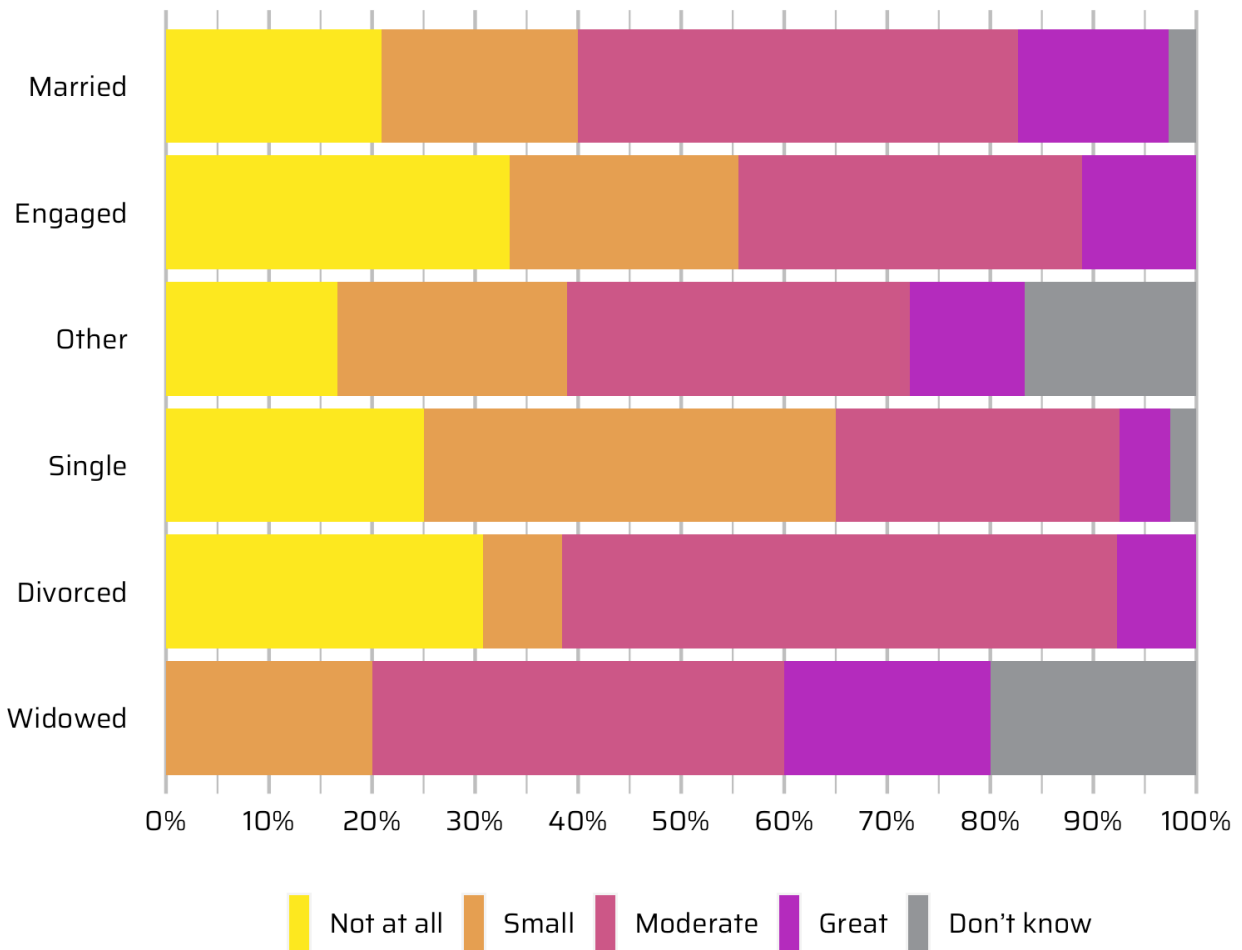


Figure 24: Mental health needs met by marital status.

Table 24: Number 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	16	15
Married	Moderate	47	43
Married	Small	21	19
Married	Not at all	23	21
Married	Don't know	3	3
Engaged	Great	1	11
Engaged	Moderate	3	33
Engaged	Small	2	22
Engaged	Not at all	3	33
Engaged	Don't know	0	0

Other	Great	2	11
Other	Moderate	6	33
Other	Small	4	22
Other	Not at all	3	17
Other	Don't know	3	17
Single	Great	2	5
Single	Moderate	11	28
Single	Small	16	40
Single	Not at all	10	25
Single	Don't know	1	2
Divorced	Great	1	8
Divorced	Moderate	7	54
Divorced	Small	1	8
Divorced	Not at all	4	31
Divorced	Don't know	0	0
Widowed	Great	1	20
Widowed	Moderate	2	40
Widowed	Small	1	20
Widowed	Not at all	0	0
Widowed	Don't know	1	20

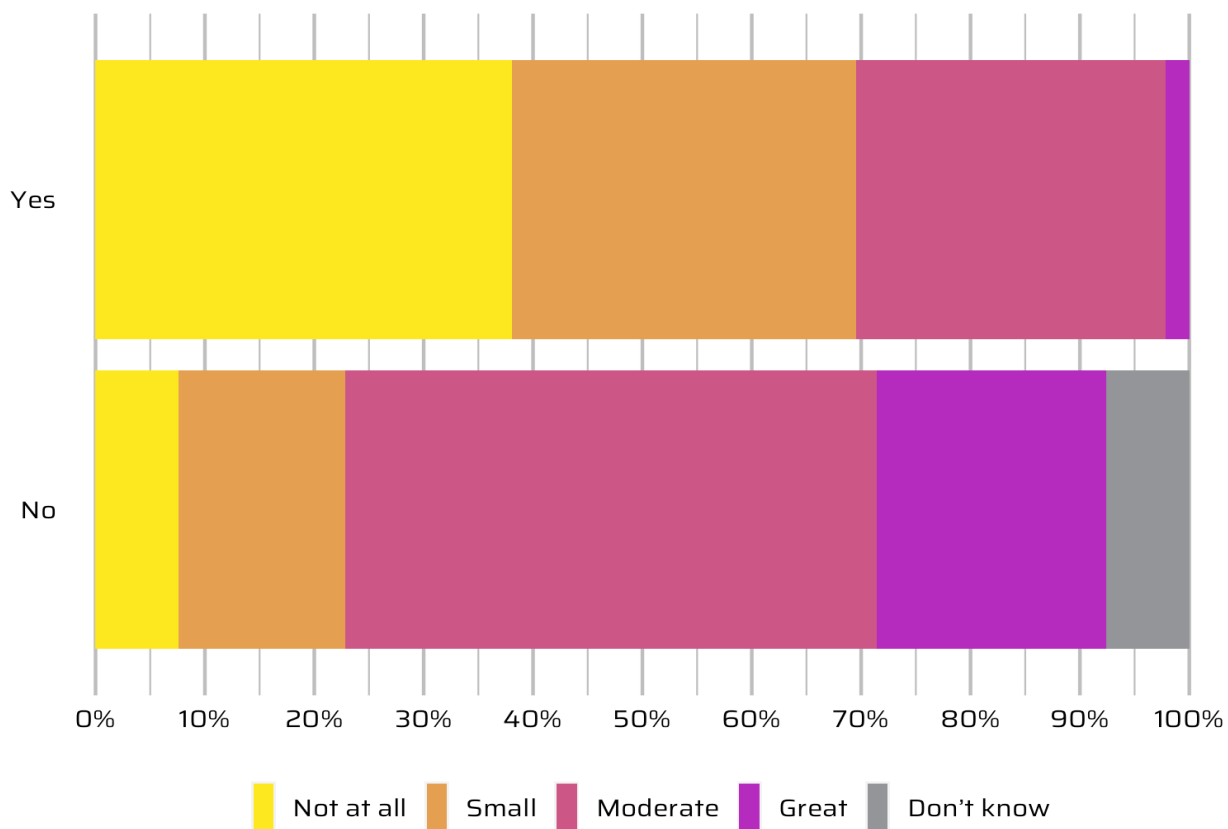


Figure 25: Anxious or Hopeless Feeling by Mental Health Need

Table 25: Number 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	2	2
Yes	Moderate	26	28
Yes	Small	29	32
Yes	Not at all	35	38
Yes	Don't know	0	0
No	Great	22	21
No	Moderate	51	49
No	Small	16	15
No	Not at all	8	8
No	Don't know	8	8



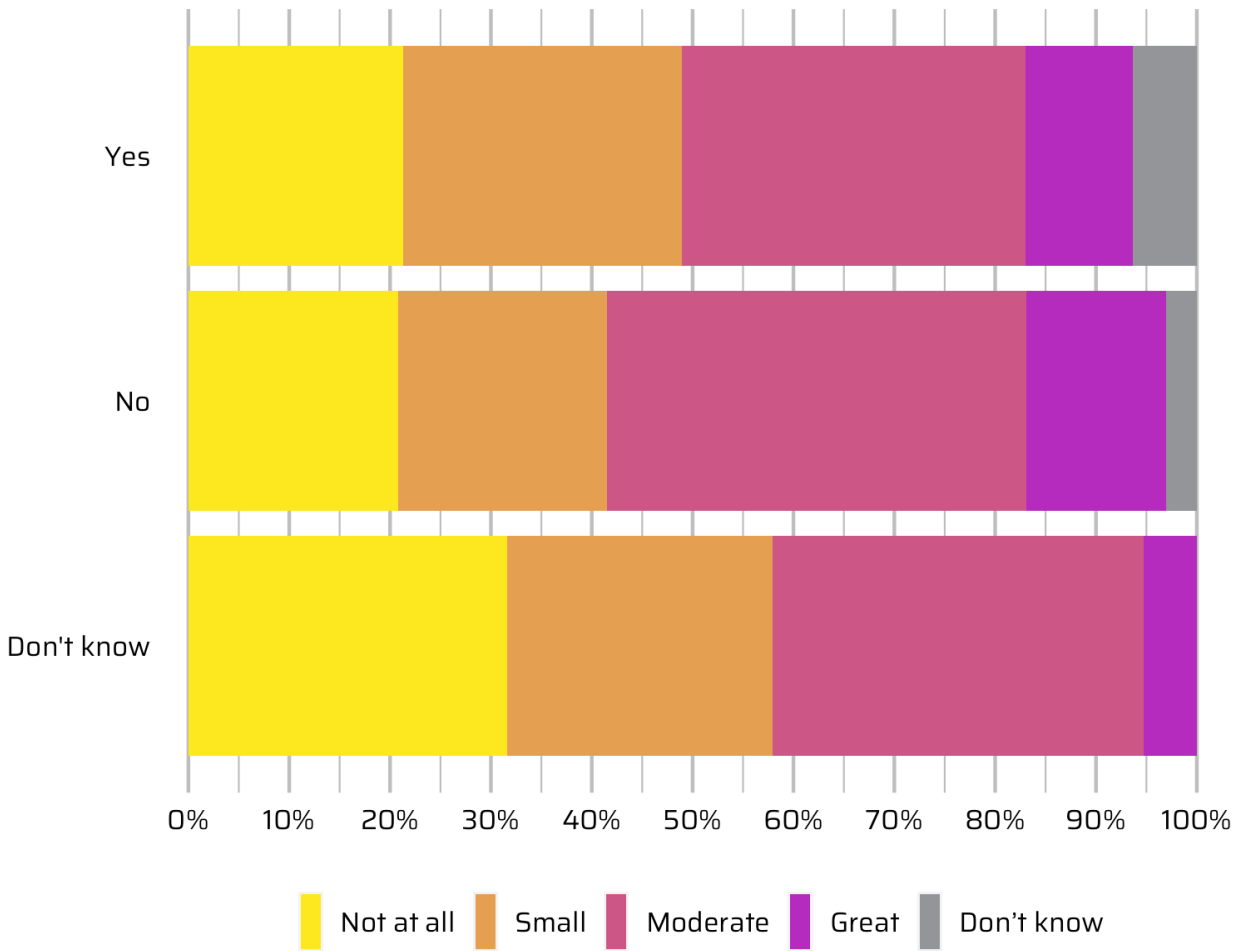


Figure 26: Delay to Care by the Extent Mental Health Needs Met

Table 26: Number 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	5	11
Yes	Moderate	16	34
Yes	Small	13	28
Yes	Not at all	10	21
Yes	Don't know	3	6
No	Great	18	14
No	Moderate	54	42
No	Small	27	21

No	Not at all	27	21
No	Don't know	4	3
Don't know	Great	1	5
Don't know	Moderate	7	37
Don't know	Small	5	26
Don't know	Not at all	6	32
Don't know	Don't know	0	0

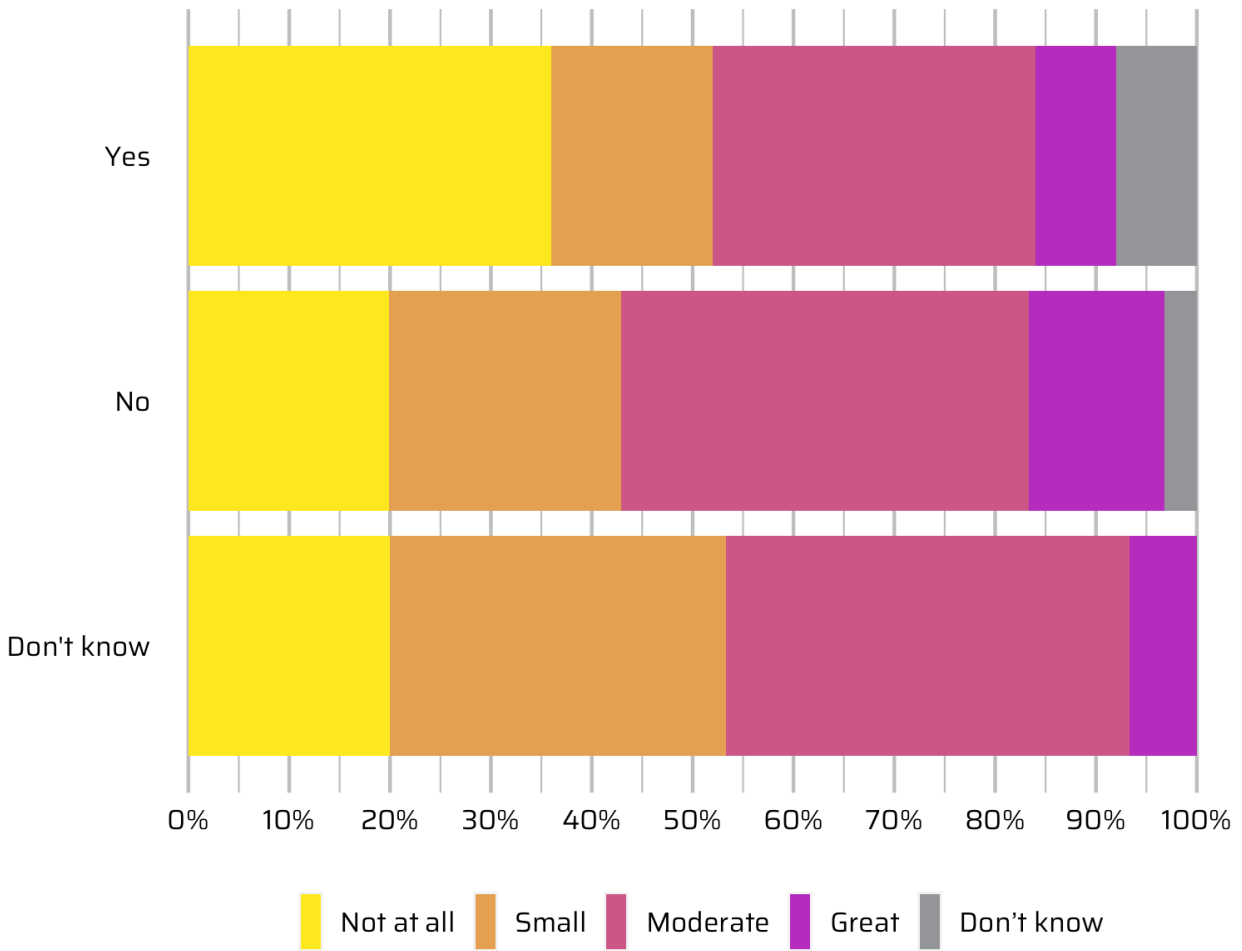


Figure 27: Cancellation of Care by the Extent Mental Health Needs Met

Table 27: Number 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	2	8
Yes	Moderate	8	32
Yes	Small	4	16
Yes	Not at all	9	36
Yes	Don't know	2	8
No	Great	21	13
No	Moderate	63	40
No	Small	36	23
No	Not at all	31	20

No	Don't know	5	3
Don't know	Great	1	7
Don't know	Moderate	6	40
Don't know	Small	5	33
Don't know	Not at all	3	20
Don't know	Don't know	0	0

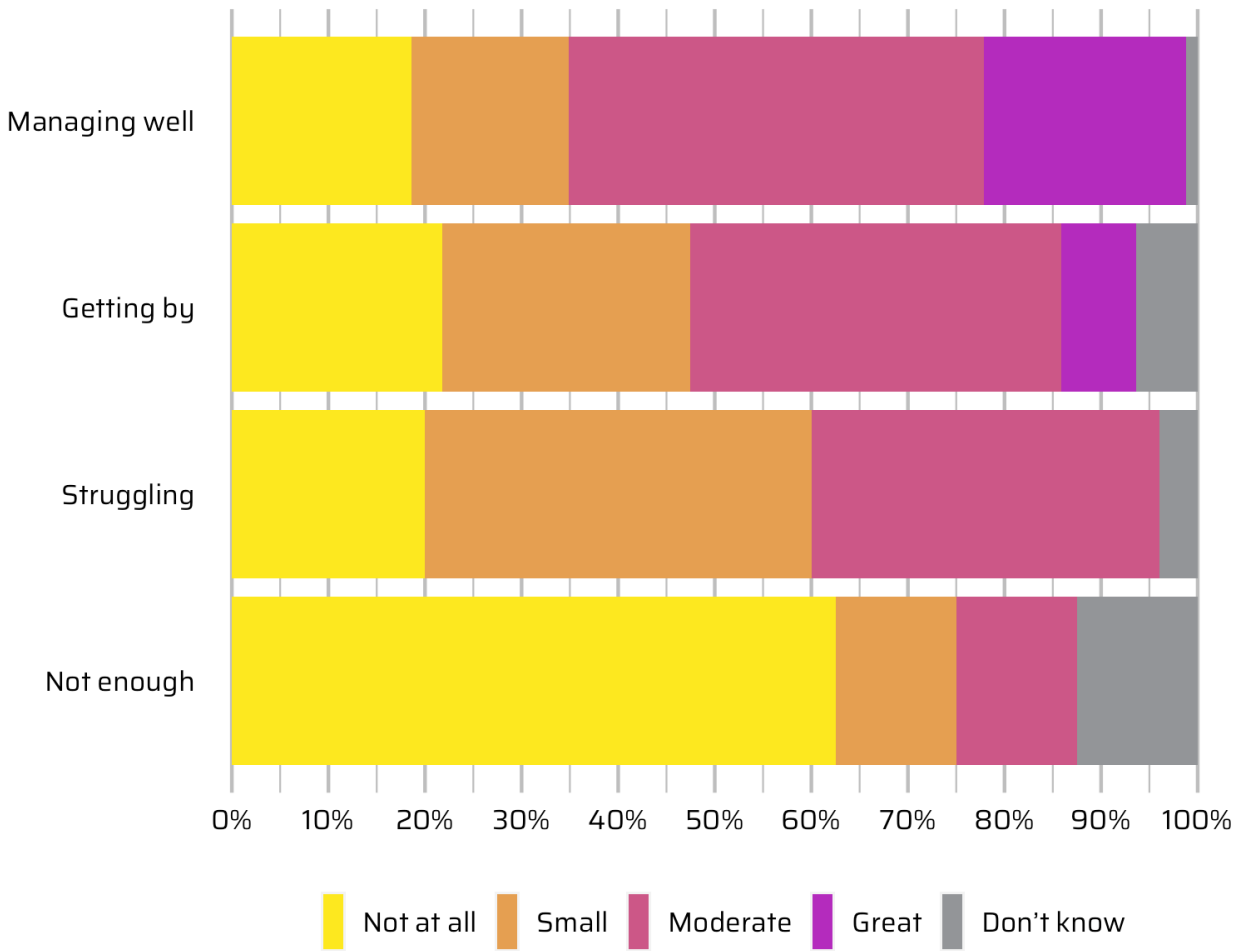


Figure 28: Financial Status by Extent Mental Health Needs Met

Table 28: Number 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	18	21
Managing well	Moderate	37	43
Managing well	Small	14	16
Managing well	Not at all	16	19
Managing well	Don't know	1	1
Getting by	Great	6	8
Getting by	Moderate	30	38
Getting by	Small	20	26
Getting by	Not at all	17	22
Getting by	Don't know	5	6

Struggling	Great	0	0
Struggling	Moderate	9	36
Struggling	Small	10	40
Struggling	Not at all	5	20
Struggling	Don't know	1	4
Not enough	Great	0	0
Not enough	Moderate	1	12
Not enough	Small	1	12
Not enough	Not at all	5	62
Not enough	Don't know	1	12

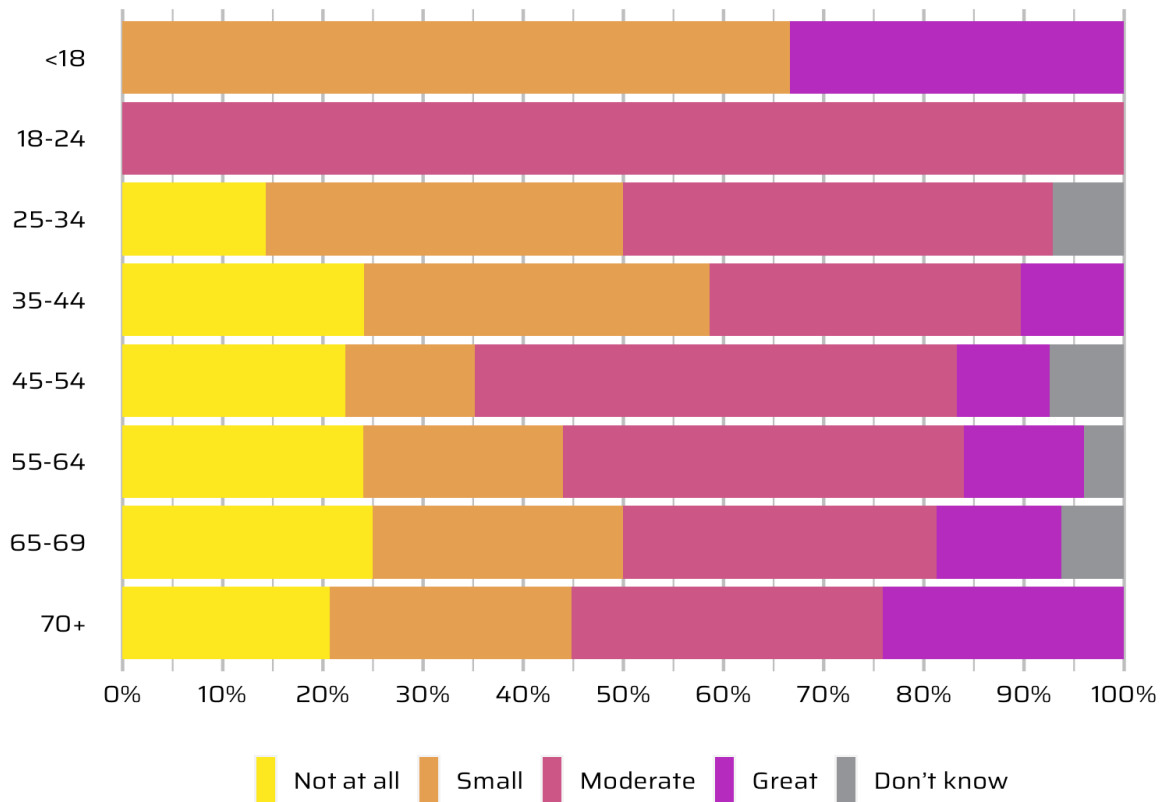


Figure 29: Age group and Extent Mental Health Needs Met.

Table 29: Number 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	0	0
<18	Small	2	67
<18	Not at all	0	0
<18	Don't know	0	0
18-24	Great	0	0
18-24	Moderate	2	100
18-24	Small	0	0
18-24	Not at all	0	0
18-24	Don't know	0	0
25-34	Great	0	0
25-34	Moderate	6	43

25-34	Small	5	36
25-34	Not at all	2	14
25-34	Don't know	1	7
35-44	Great	3	10
35-44	Moderate	9	31
35-44	Small	10	34
35-44	Not at all	7	24
35-44	Don't know	0	0
45-54	Great	5	9
45-54	Moderate	26	48
45-54	Small	7	13
45-54	Not at all	12	22
45-54	Don't know	4	7
55-64	Great	6	12
55-64	Moderate	20	40
55-64	Small	10	20
55-64	Not at all	12	24
55-64	Don't know	2	4
65-69	Great	2	12
65-69	Moderate	5	31
65-69	Small	4	25
65-69	Not at all	4	25
65-69	Don't know	1	6
70+	Great	7	24
70+	Moderate	9	31
70+	Small	7	24
70+	Not at all	6	21
70+	Don't know	0	0



Mental Wellbeing

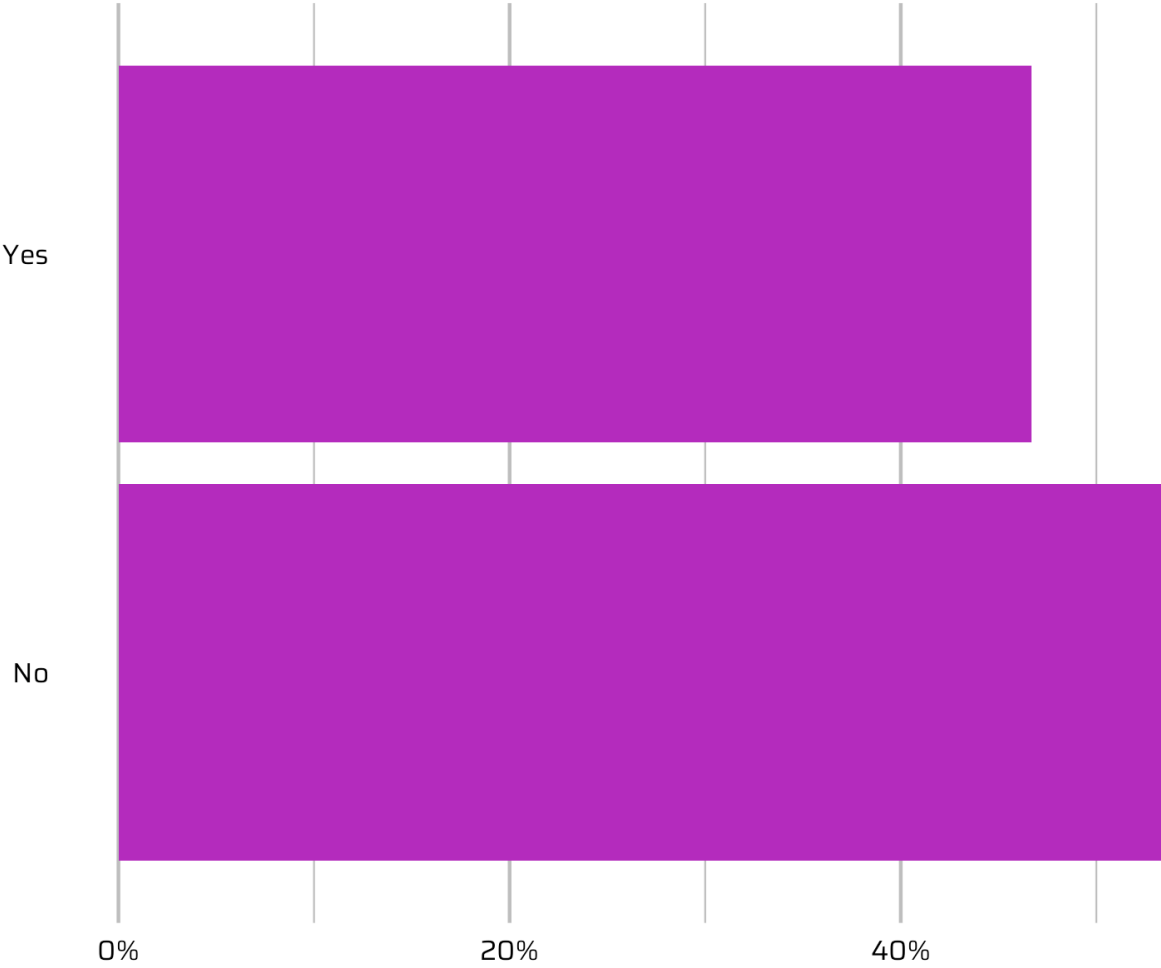


Figure 30: Anxious or hopeless feeling.

Table 30: Number and types of responses: Anxious or hopeless feeling.

Anxious or Hopeless	Respondents	Percentage
Yes	92	47
No	105	53

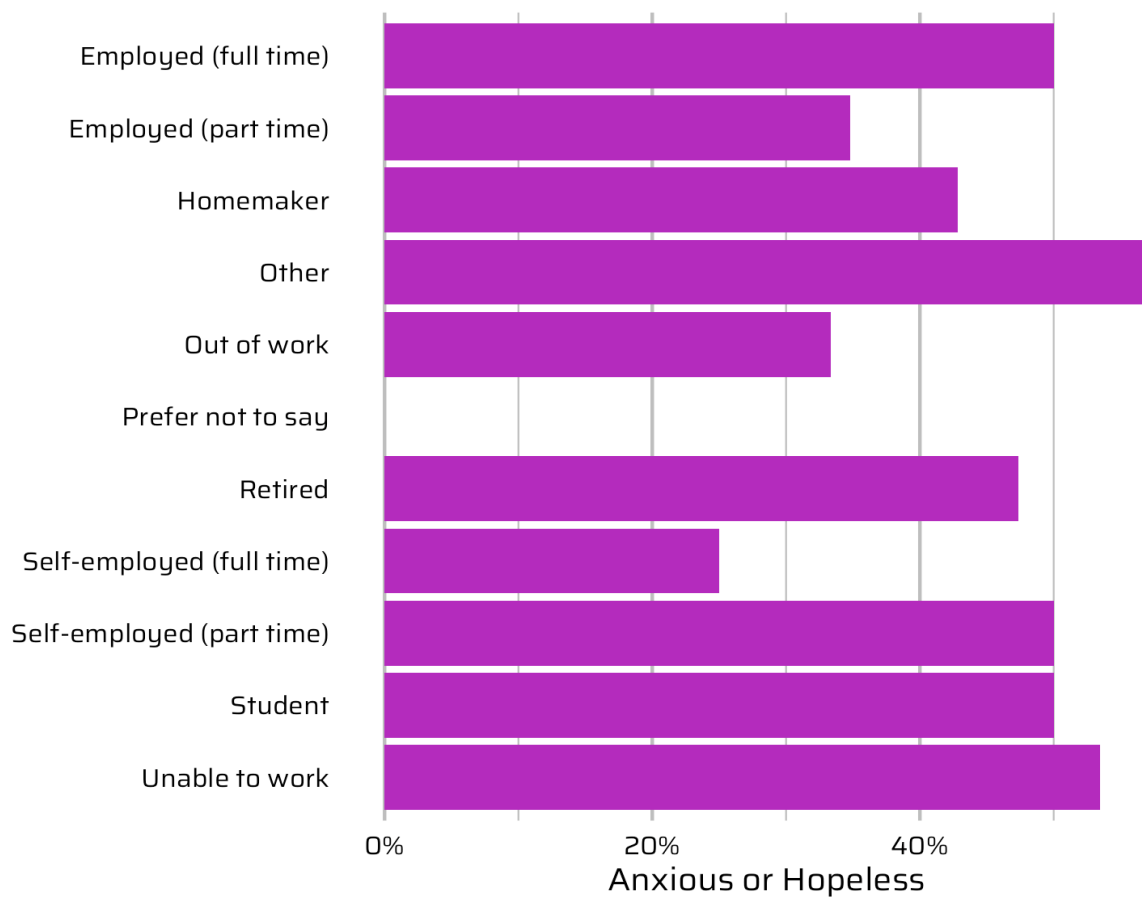


Figure 31: Anxious or hopeless feeling by employment status.

Table 31: Anxious or hopeless feeling by employment status.

Employment Status	Anxious or Hopeless	Respondents	Percentage
Employed (full time)	Yes	21	50
Employed (full time)	No	21	50
Employed (part time)	Yes	8	35
Employed (part time)	No	15	65
Homemaker	Yes	3	43
Homemaker	No	4	57
Other	Yes	4	57
Other	No	3	43
Out of work	Yes	2	33
Out of work	No	4	67
Prefer not to say	Yes	0	0
Prefer not to say	No	1	100
Retired	Yes	27	47
Retired	No	30	53

Self-employed (full time)	Yes	1	25
Self-employed (full time)	No	3	75
Self-employed (part time)	Yes	1	50
Self-employed (part time)	No	1	50
Student	Yes	1	50
Student	No	1	50
Unable to work	Yes	23	53
Unable to work	No	20	47

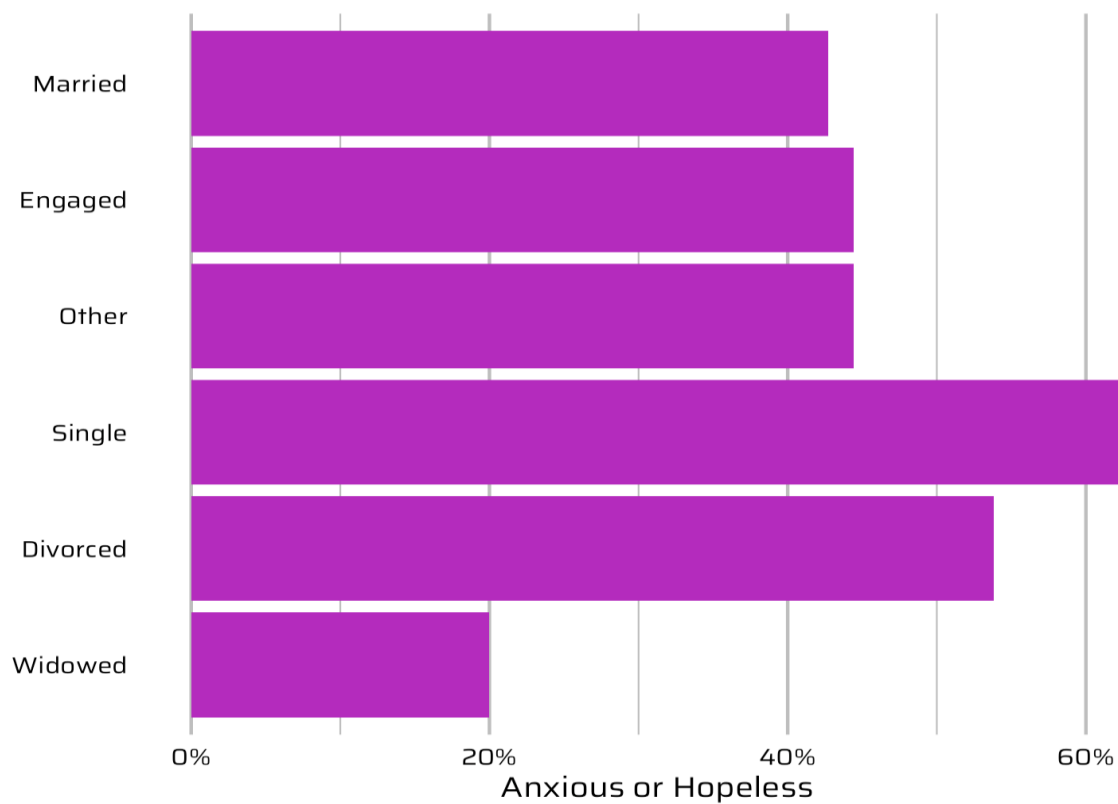


Figure 32: Anxious or hopelessness feeling by marital status

Table 32: Anxious or hopelessness feeling by marital status.

Marital Status	Anxious or Hopeless	Respondents	Percentage
Married	Yes	47	43
Married	No	63	57
Engaged	Yes	4	44
Engaged	No	5	56
Other	Yes	8	44
Other	No	10	56
Single	Yes	25	62
Single	No	15	38
Divorced	Yes	7	54
Divorced	No	6	46
Widowed	Yes	1	20
Widowed	No	4	80

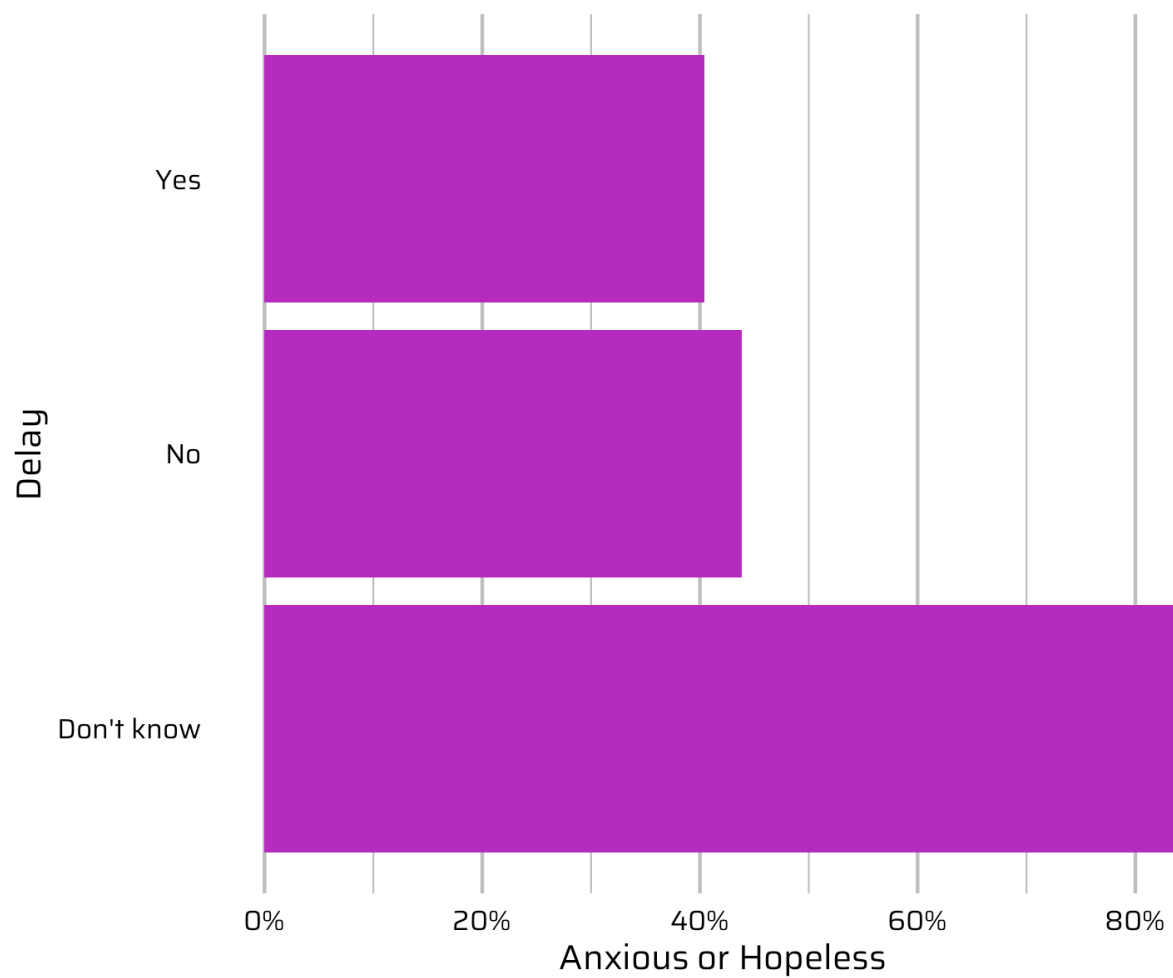


Figure 33: Delays to care by feelings of anxiety or hopelessness.

Table 33: Number 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	19	40
Yes	No	28	60
No	Yes	57	44
No	No	73	56
Don't know	Yes	16	84
Don't know	No	3	16

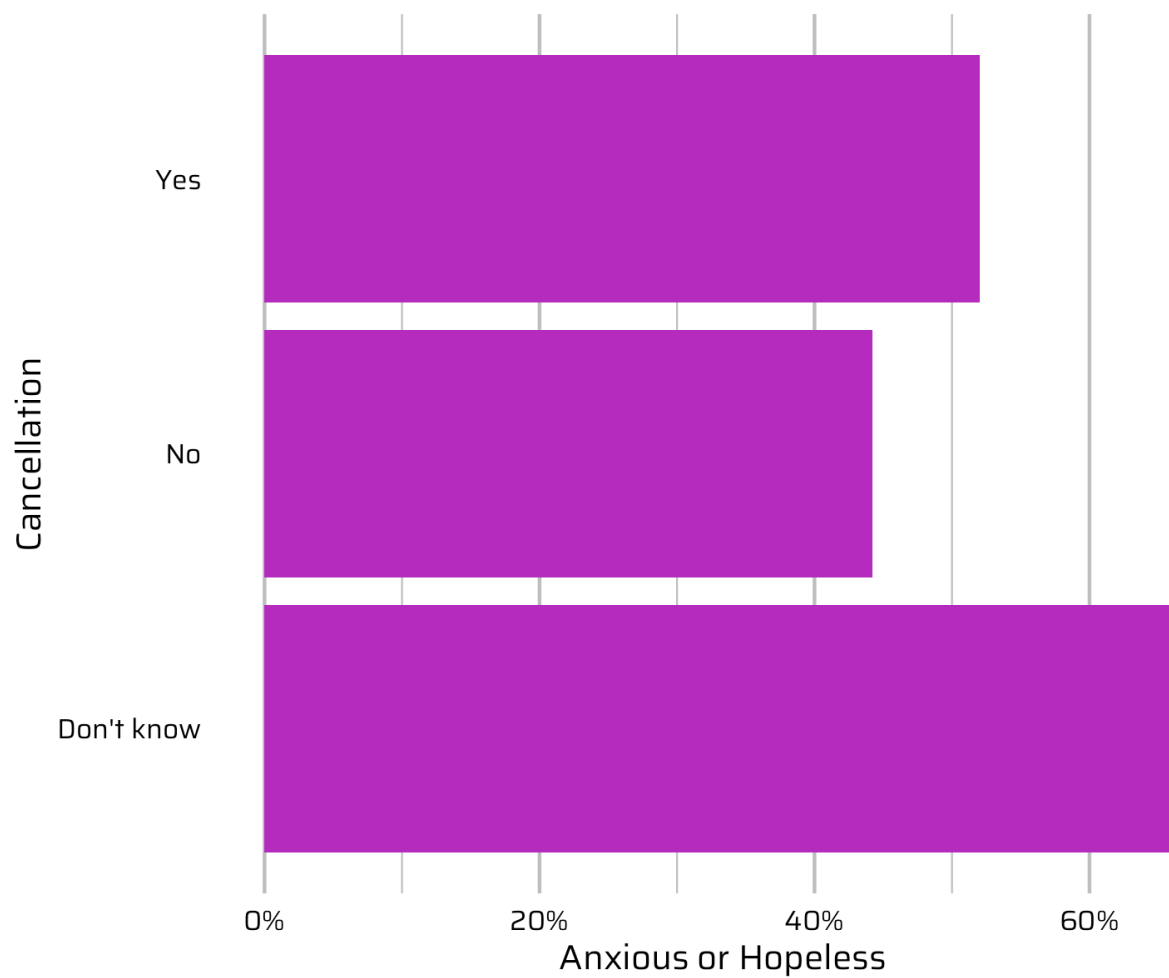


Figure 34: Cancellations to care by feelings of anxiety or hopelessness.

Table 34: Number 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	13	52
Yes	No	12	48
No	Yes	69	44
No	No	87	56
Don't know	Yes	10	67
Don't know	No	5	33

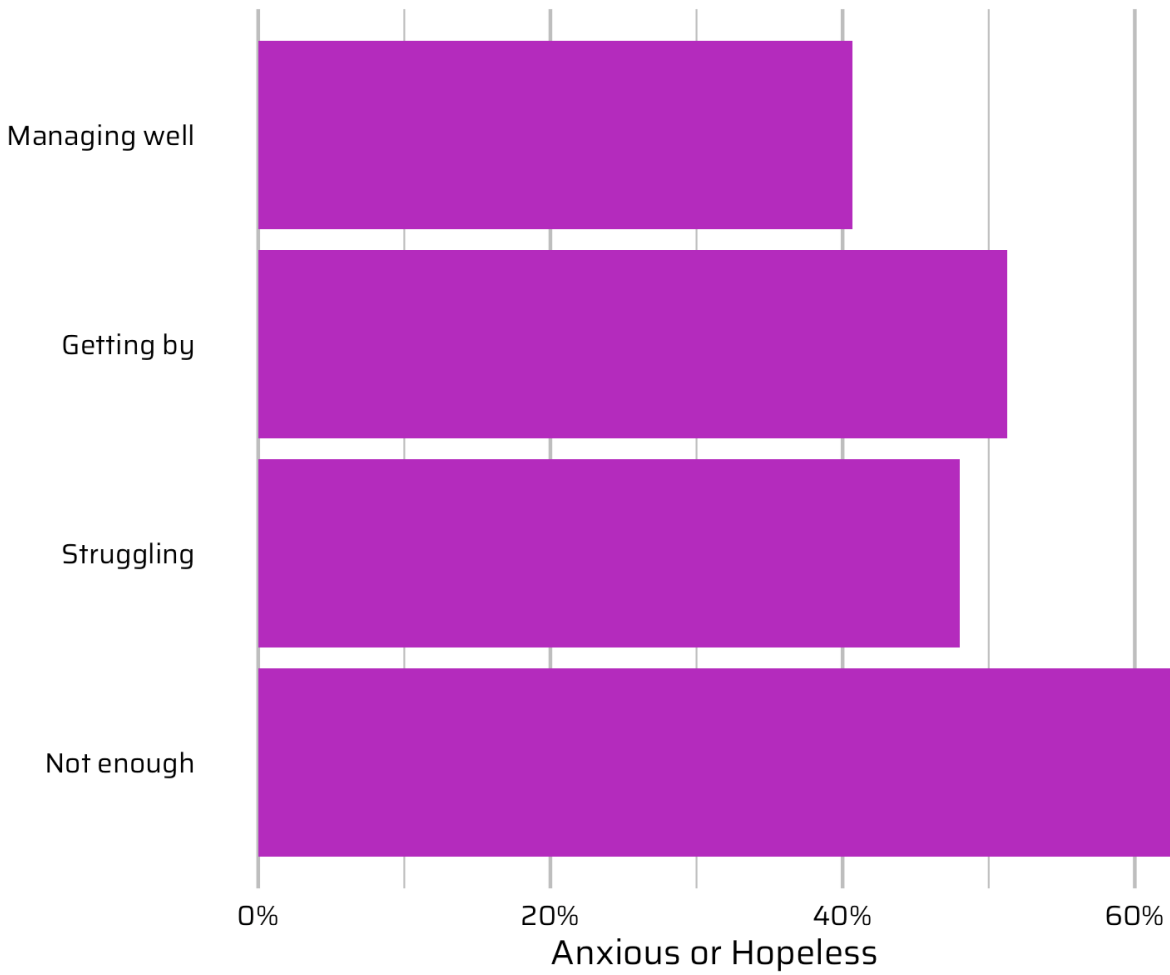


Figure 35: Anxious or hopeless feeling by financial status.

Table 35: Anxious or hopeless feeling by financial status.

Financial Status	Anxious or Hopeless	Respondents	Percentage
Managing well	Yes	35	41
Managing well	No	51	59
Getting by	Yes	40	51
Getting by	No	38	49
Struggling	Yes	12	48
Struggling	No	13	52
Not enough	Yes	5	62
Not enough	No	3	38

Emergency Care

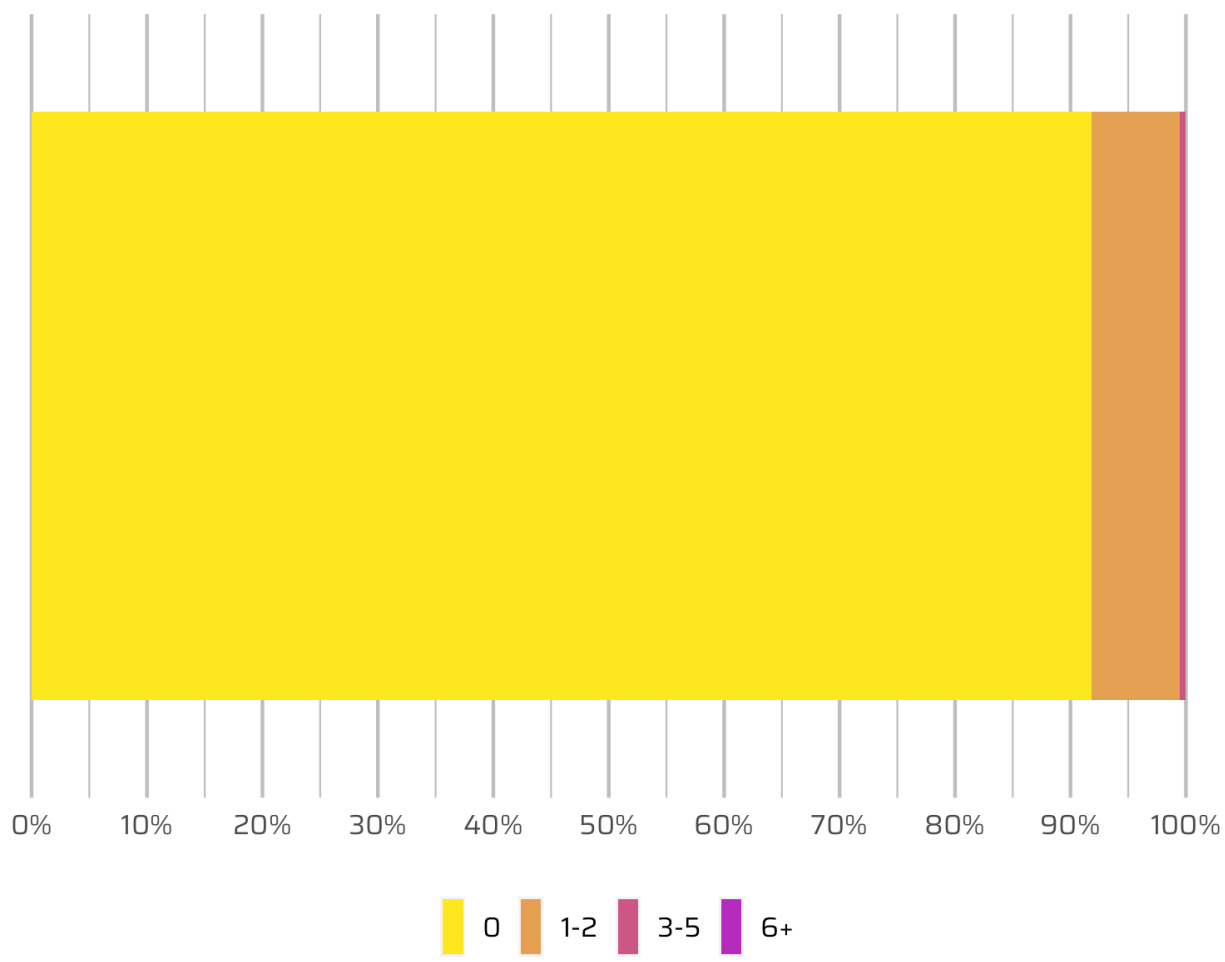


Figure 36: How many times have you sought emergency care in the last 8 weeks?

Table 36: Number of responses to the question 'How many times have you sought emergency support in the past 8 weeks?

Frequency	Respondents	Percentage
6+	0	0
3-5	1	1
1-2	15	8
0	180	92



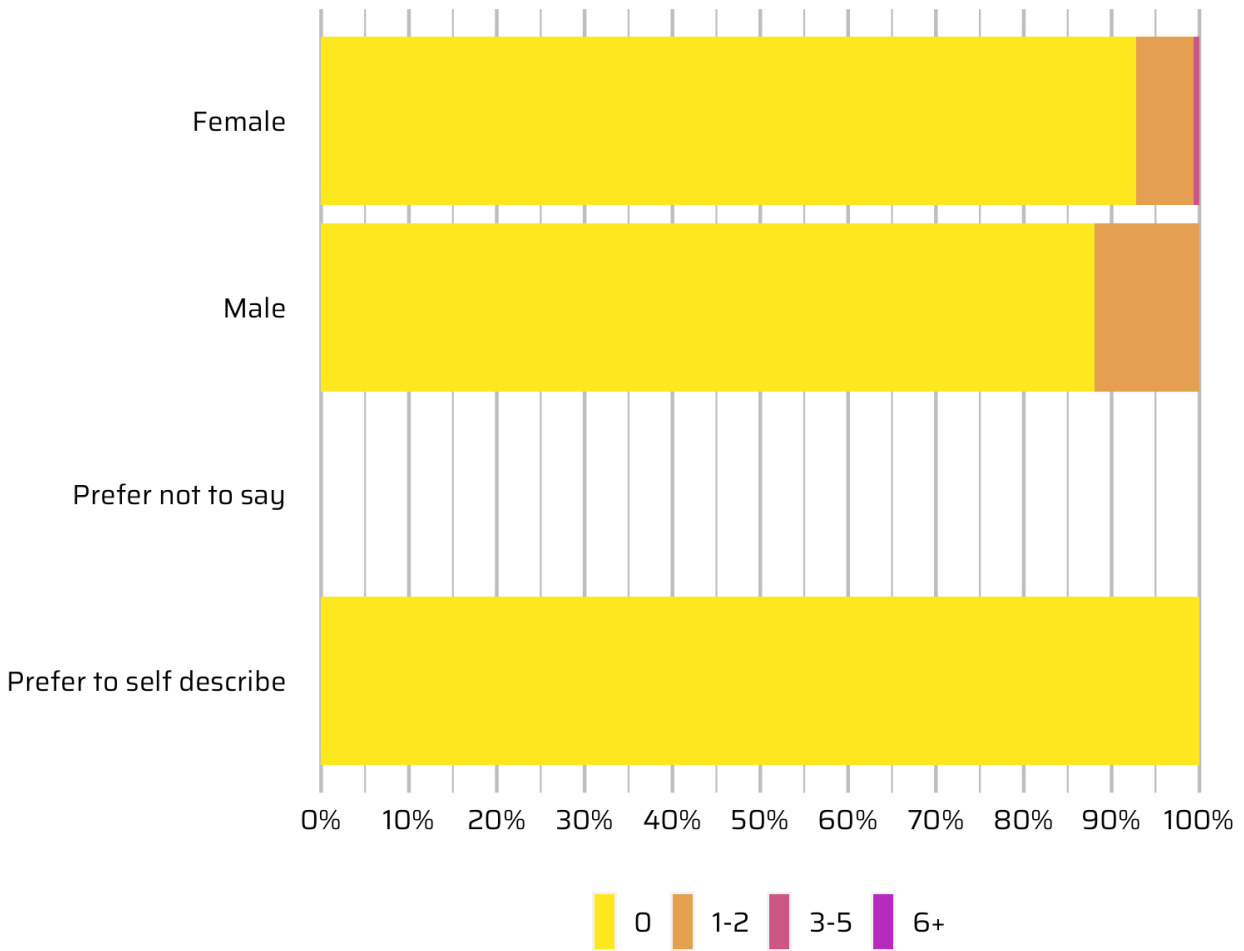


Figure 37: Emergency support by gender.

Table 37: Number of responses to the question 'How many times have you sought emergency support in the past 8 weeks by gender.

Gender	Frequency	Respondents	Percentage
Female	6+	0	0
Female	3-5	1	1
Female	1-2	10	7
Female	0	142	93
Male	6+	0	0
Male	3-5	0	0
Male	1-2	5	12
Male	0	37	88
Prefer not to say	6+	0	NaN
Prefer not to say	3-5	0	NaN

Prefer not to say	1-2	0	NaN
Prefer not to say	0	0	NaN
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

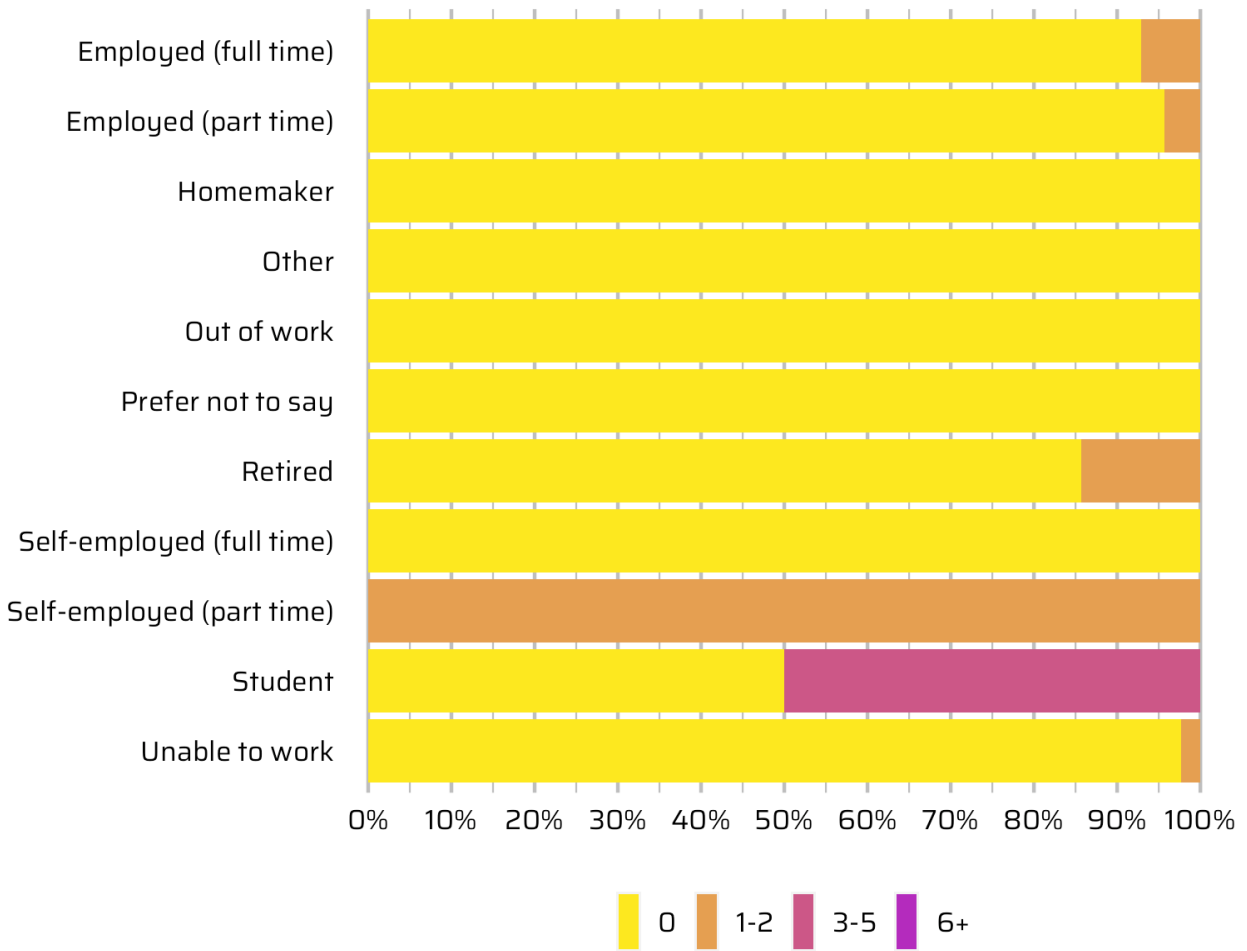


Figure 38: Emergency support by employment status.

Table 38: Number of responses to the question 'How many times have you sought emergency support in the past 8 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	3	7
Employed (full time)	0	39	93
Employed (part time)	6+	0	0
Employed (part time)	3-5	0	0
Employed (part time)	1-2	1	4
Employed (part time)	0	22	96
Homemaker	6+	0	0
Homemaker	3-5	0	0

Homemaker	1-2	0	0
Homemaker	0	7	100
Other	6+	0	0
Other	3-5	0	0
Other	1-2	0	0
Other	0	7	100
Out of work	6+	0	0
Out of work	3-5	0	0
Out of work	1-2	0	0
Out of work	0	6	100
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
Retired	6+	0	0
Retired	3-5	0	0
Retired	1-2	8	14
Retired	0	48	86
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	4	100
Self-employed (part time)	6+	0	0
Self-employed (part time)	3-5	0	0
Self-employed (part time)	1-2	2	100
Self-employed (part time)	0	0	0
Student	6+	0	0
Student	3-5	1	50
Student	1-2	0	0
Student	0	1	50
Unable to work	6+	0	0

Unable to work	3-5	0	0
Unable to work	1-2	1	2
Unable to work	0	42	98

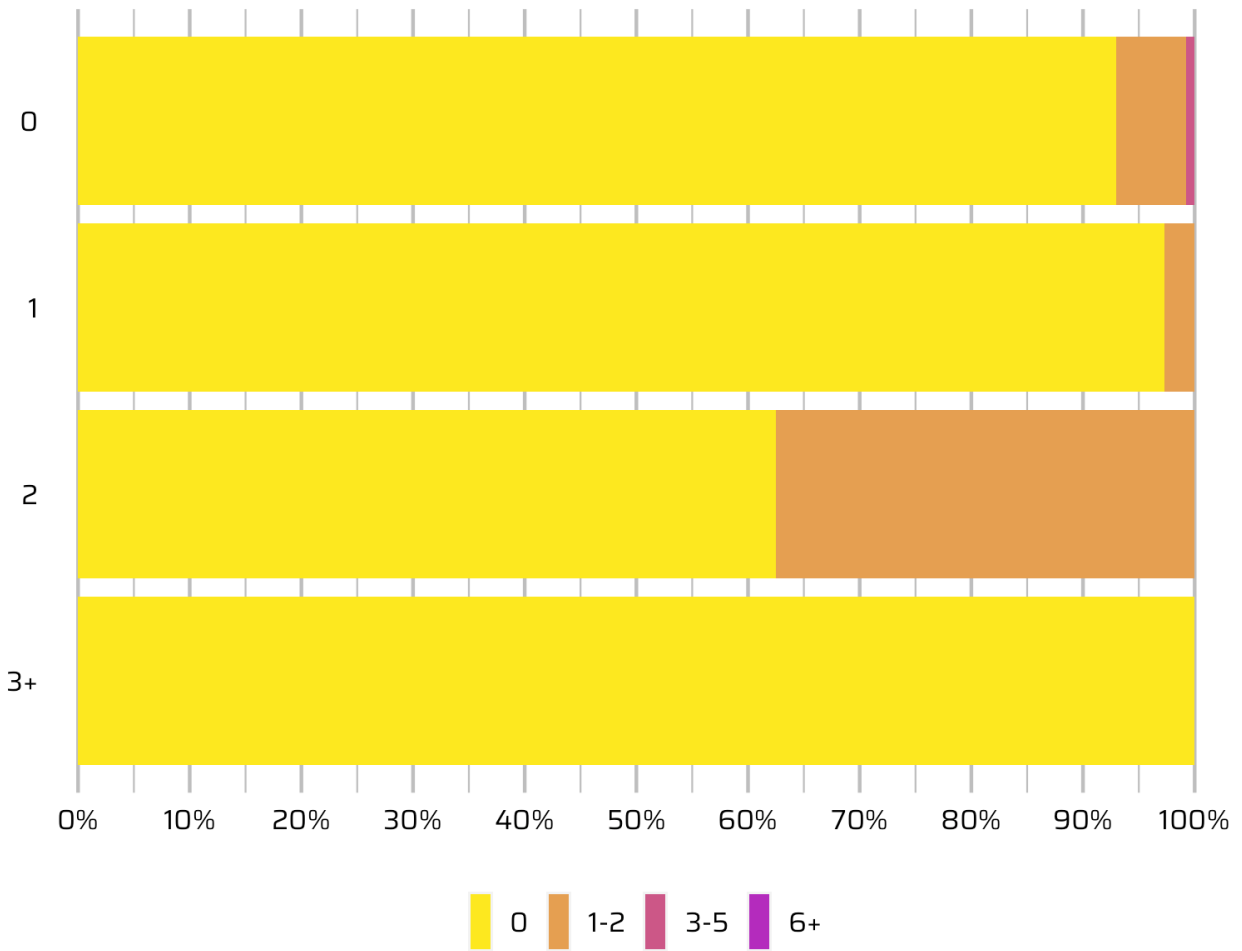


Figure 39: Number of dependents by frequency of emergency support.

Table 39: Number of responses to the question 'How many times have you sought emergency support in the past 8 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	119	93
1	6+	0	0
1	3-5	0	0
1	1-2	1	3
1	0	36	97
2	6+	0	0
2	3-5	0	0

2	1-2	6	38
2	0	10	62
3+	6+	0	0
3+	3-5	0	0
3+	1-2	0	0
3+	0	9	100

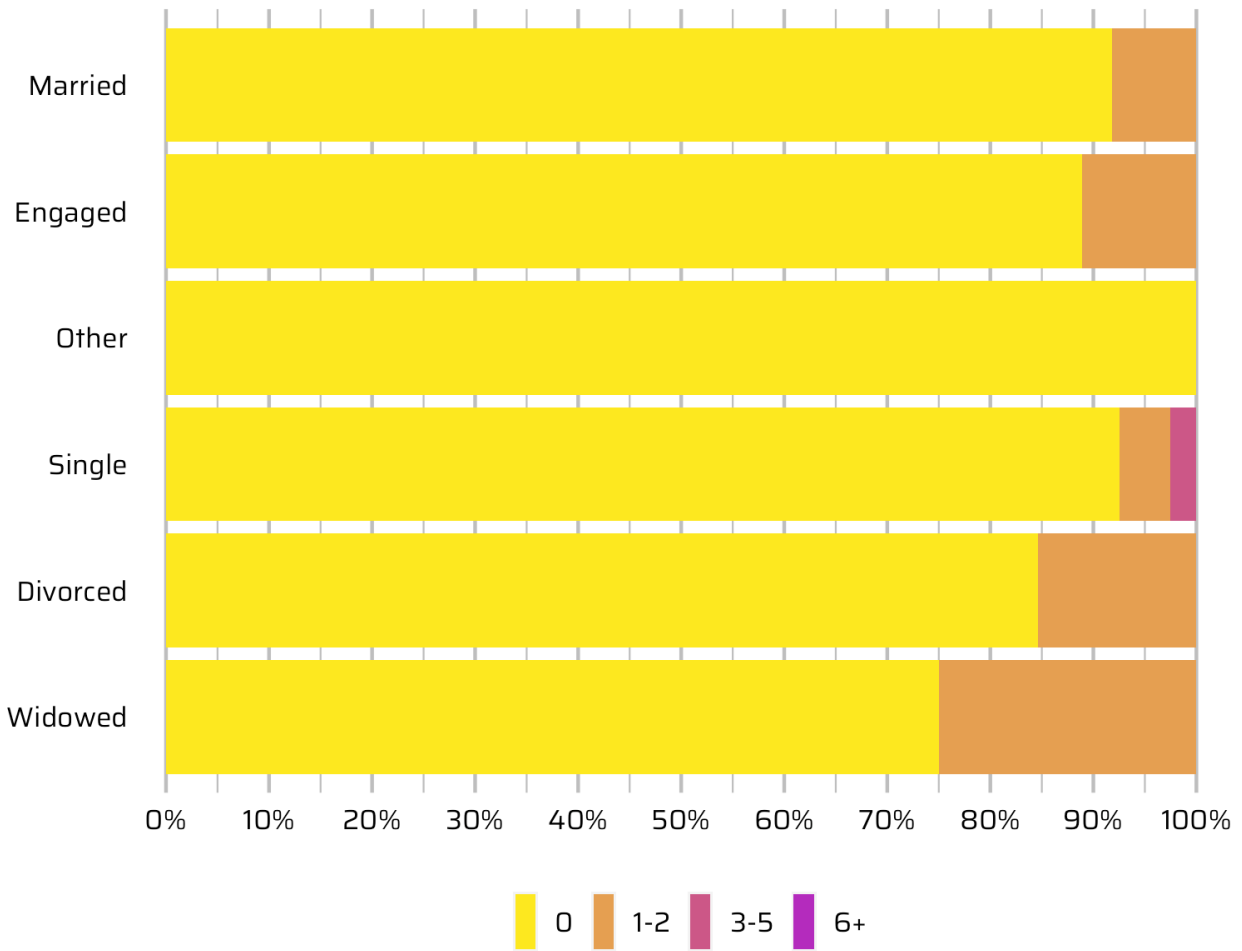


Figure 40: Marital status by frequency of emergency support.

Table 40: Number of responses to the question 'How many times have you sort emergency support im the past 8 weeks?' by marital status.

Marital Status	Frequency	Respondents	Percentage
Married	6+	0	0
Married	3-5	0	0
Married	1-2	9	8
Married	0	101	92
Engaged	6+	0	0
Engaged	3-5	0	0
Engaged	1-2	1	11
Engaged	0	8	89
Other	6+	0	0
Other	3-5	0	0



Other	1-2	0	0
Other	0	18	100
Single	6+	0	0
Single	3-5	1	2
Single	1-2	2	5
Single	0	37	92
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	1	25
Widowed	0	3	75

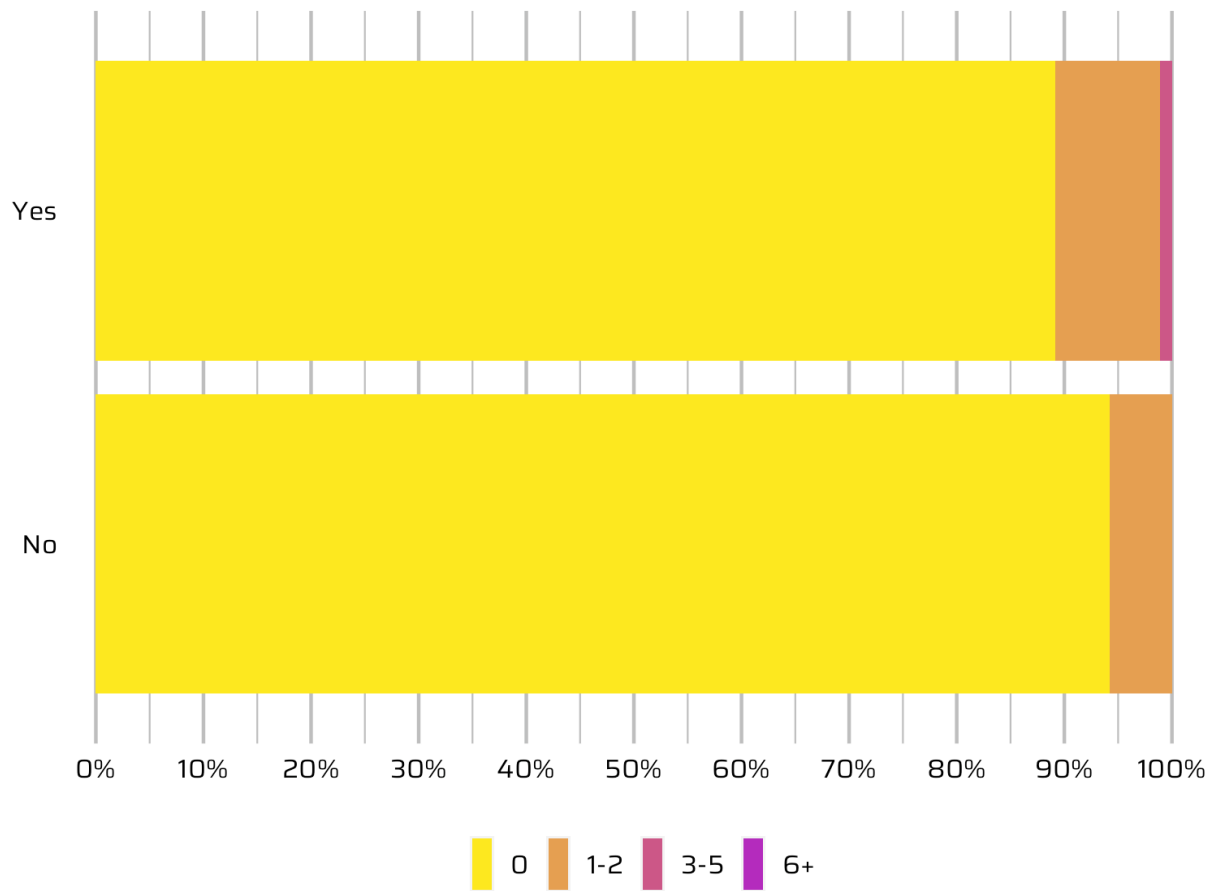


Figure 41: Anxious or hopeless feeling by frequency of emergency support.

Table 41: Number 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+	0	0
Yes	3-5	1	1
Yes	1-2	9	10
Yes	0	82	89
No	6+	0	0
No	3-5	0	0
No	1-2	6	6
No	0	98	94

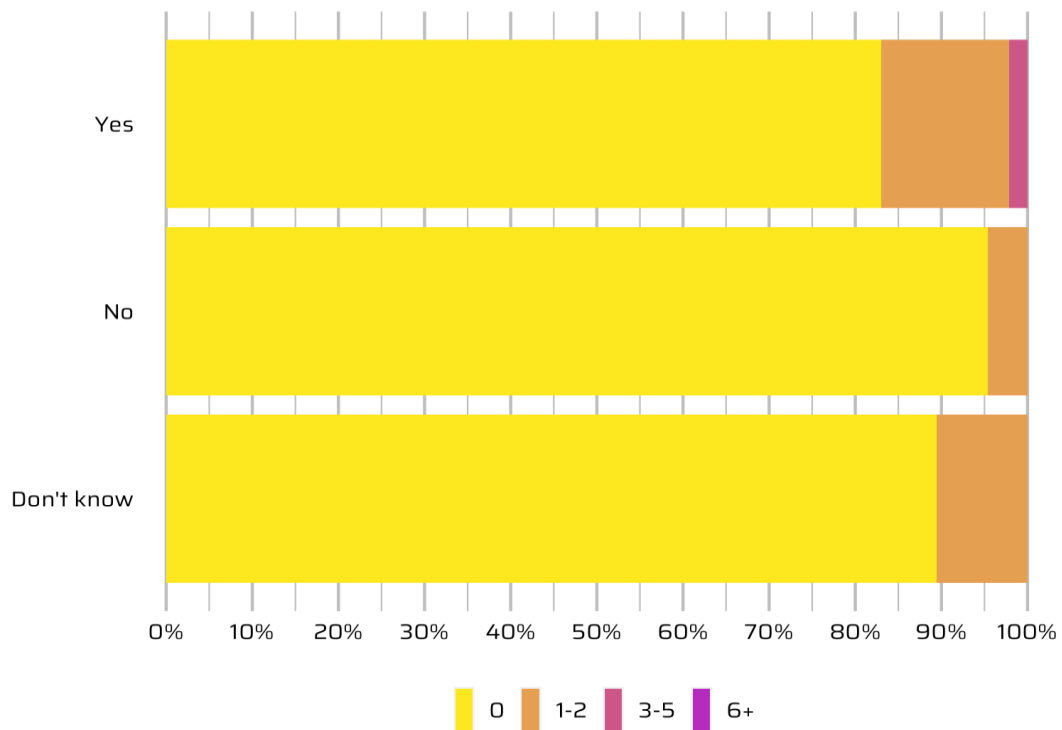


Figure 42: Delays to care and frequency of emergency support.

Table 42: Number 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+	0	0
Yes	3-5	1	2
Yes	1-2	7	15
Yes	0	39	83
No	6+	0	0
No	3-5	0	0
No	1-2	6	5
No	0	124	95
Don't know	6+	0	0
Don't know	3-5	0	0
Don't know	1-2	2	11
Don't know	0	17	89

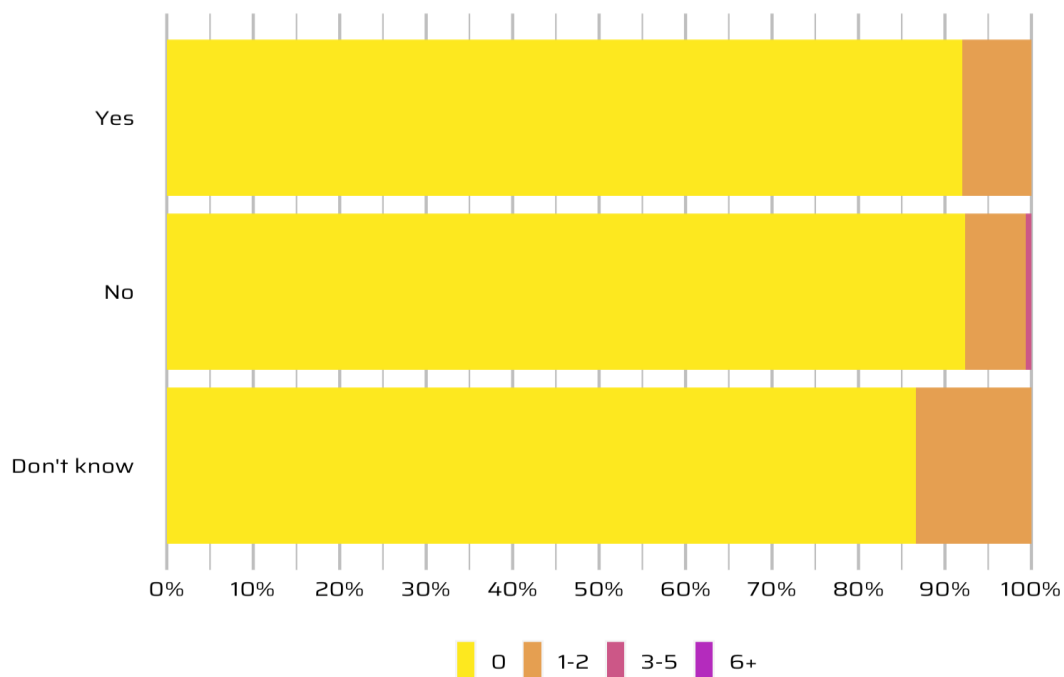


Figure 43: Cancellation of care and frequency of emergency support.

Table 43: Number of responses to the question 'How many times have you sought emergency support in the past 8 weeks?' by those who reported cancellations to care.

Cancellation	Frequency	Respondents	Percentage
Yes	6+	0	0
Yes	3-5	0	0
Yes	1-2	2	8
Yes	0	23	92
No	6+	0	0
No	3-5	1	1
No	1-2	11	7
No	0	144	92
Don't know	6+	0	0
Don't know	3-5	0	0
Don't know	1-2	2	13
Don't know	0	13	87

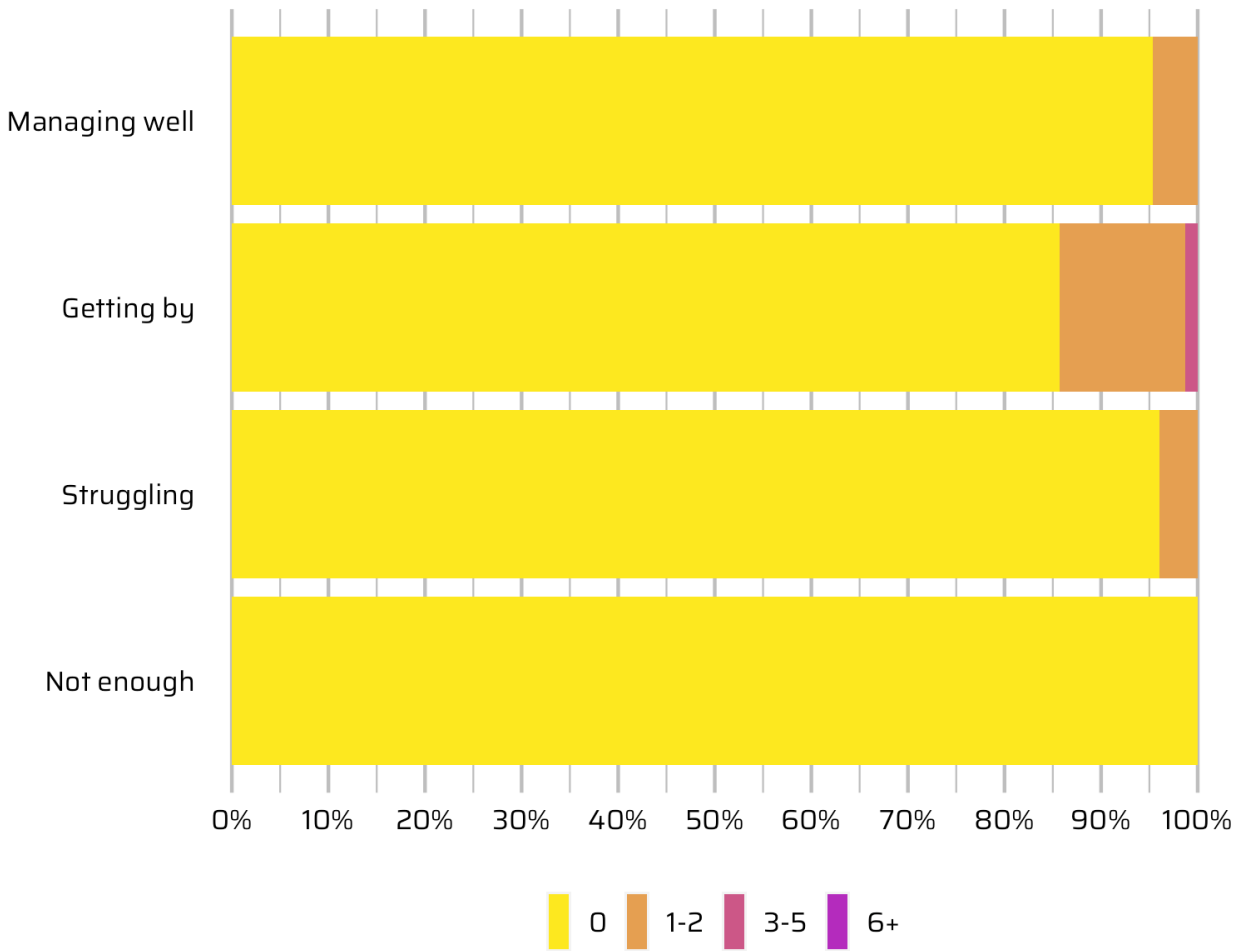


Figure 44: Financial status and frequency of emergency support.

Table 44: Number of responses to the question 'How many times have you sought emergency support in the past 8 weeks?' by financial status.

Financial Status	Frequency	Respondents	Percentage
Managing well	6+	0	0
Managing well	3-5	0	0
Managing well	1-2	4	5
Managing well	0	82	95
Getting by	6+	0	0
Getting by	3-5	1	1
Getting by	1-2	10	13
Getting by	0	66	86
Struggling	6+	0	0
Struggling	3-5	0	0

Struggling	1-2	1	4
Struggling	0	24	96
Not enough	6+	0	0
Not enough	3-5	0	0
Not enough	1-2	0	0
Not enough	0	8	100

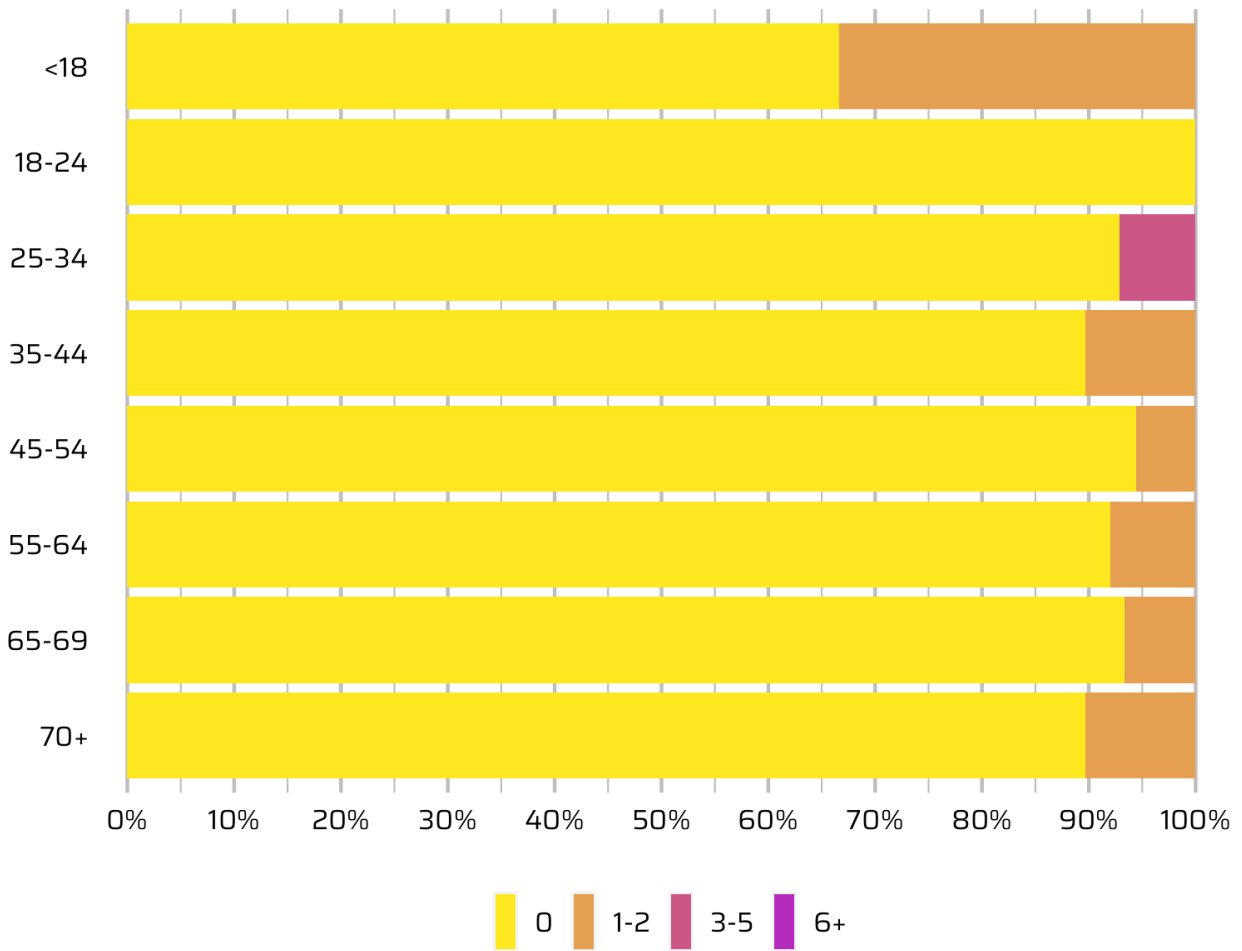


Figure 45: Age and frequency of emergency support.

Table 45: Number 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	1	33
<18	0	2	67
18-24	6+	0	0
18-24	3-5	0	0
18-24	1-2	0	0
18-24	0	2	100
25-34	6+	0	0
25-34	3-5	1	7

25-34	1-2	0	0
25-34	0	13	93
35-44	6+	0	0
35-44	3-5	0	0
35-44	1-2	3	10
35-44	0	26	90
45-54	6+	0	0
45-54	3-5	0	0
45-54	1-2	3	6
45-54	0	51	94
55-64	6+	0	0
55-64	3-5	0	0
55-64	1-2	4	8
55-64	0	46	92
65-69	6+	0	0
65-69	3-5	0	0
65-69	1-2	1	7
65-69	0	14	93
70+	6+	0	0
70+	3-5	0	0
70+	1-2	3	10
70+	0	26	90



Changes to Emergency Support

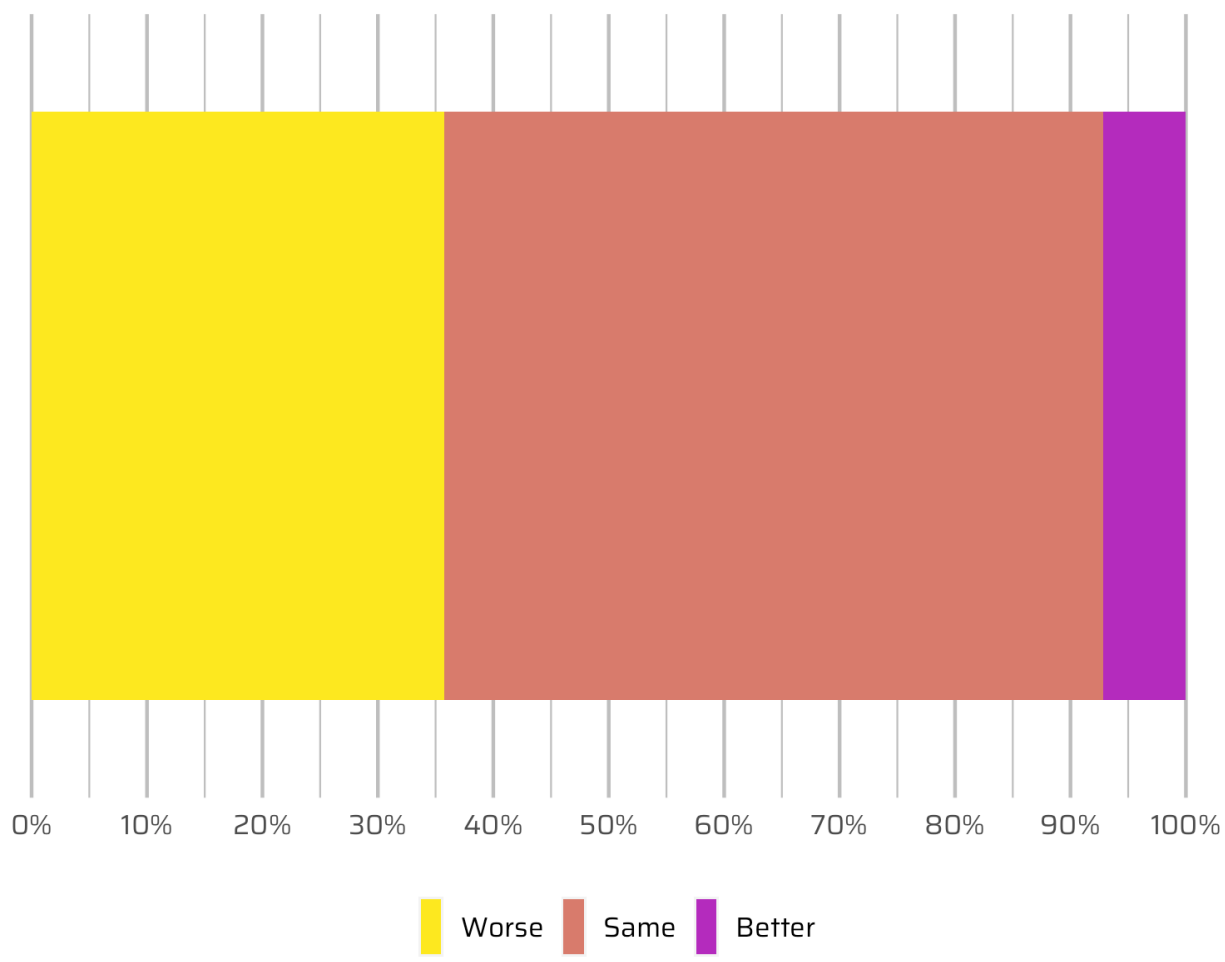


Figure 46: Change to emergency support.

Table 46: Number of responses to the question 'Overall, do you feel that you experience of emergency care was different during the COVID-19 pandemic compared to before the pandemic?'

Change	Respondents	Percentage
Better	1	7
Same	8	57
Worse	5	36

Accessed Support

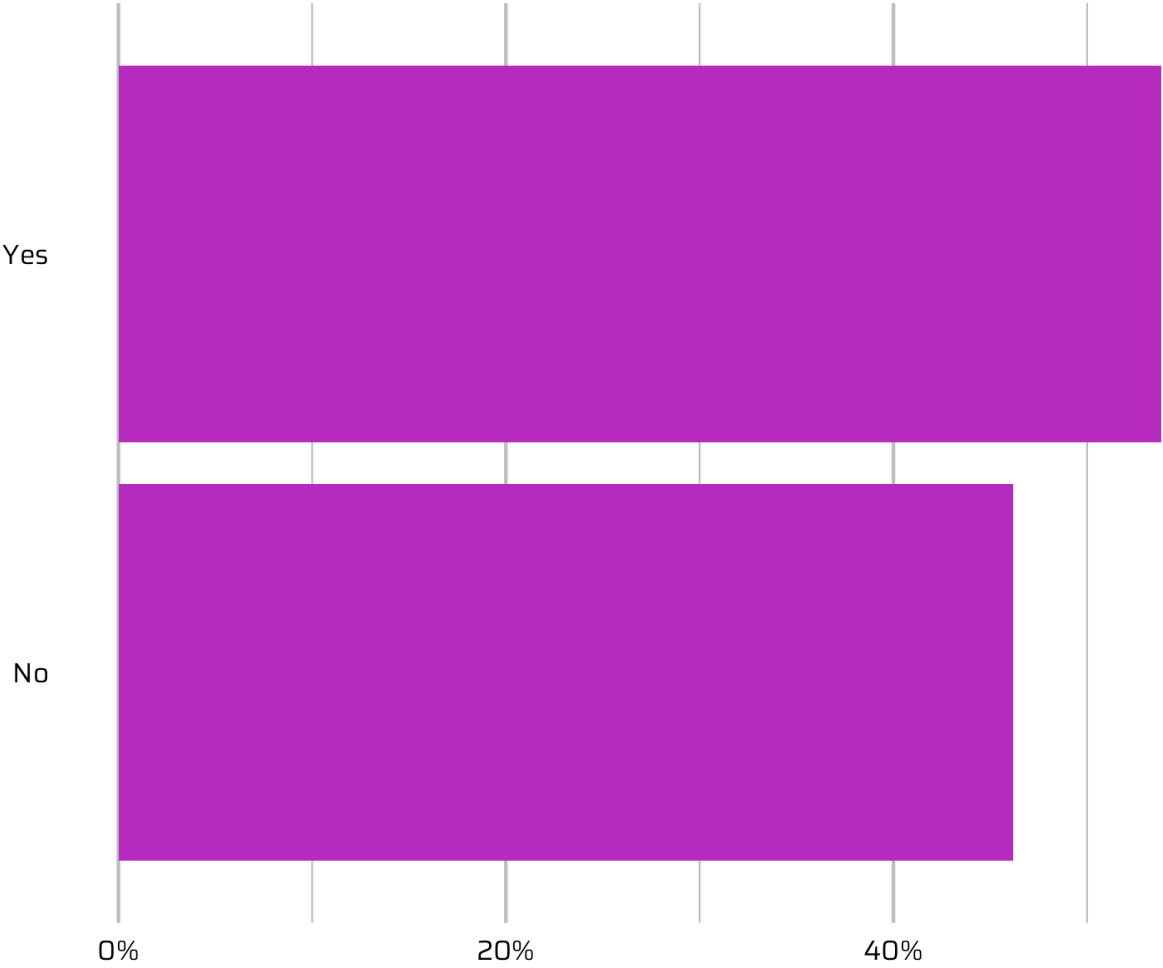


Figure 47:Proportion of respondents who had accessed support in the past 8 weeks.

Table 47: Number of responses to the question 'Have you accessed treatment, care and support for your condition in the last 8 weeks?'

Access	Respondents	Percentage
Yes	106	54
No	91	46

Medical Appointment

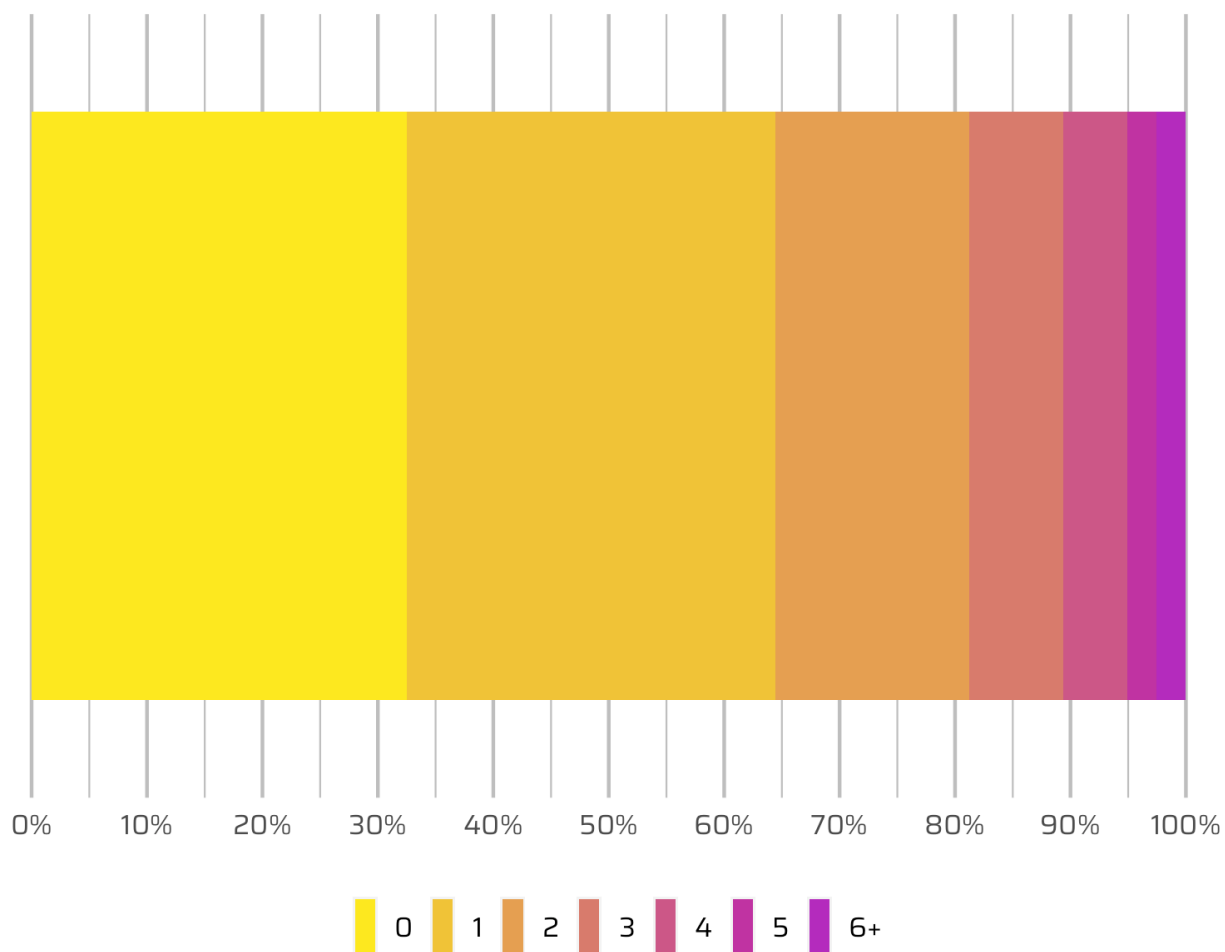


Figure 48: Number of Medical Appointments in the past 8 weeks.

Table 48: Number of responses to the question 'How many medical appointments (including remote appointments) have you had in the last 8 weeks?'

Number	Respondents	Percentage
6+	5	3
5	5	3
4	11	6
3	16	8
2	33	17
1	63	32
0	64	32

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.

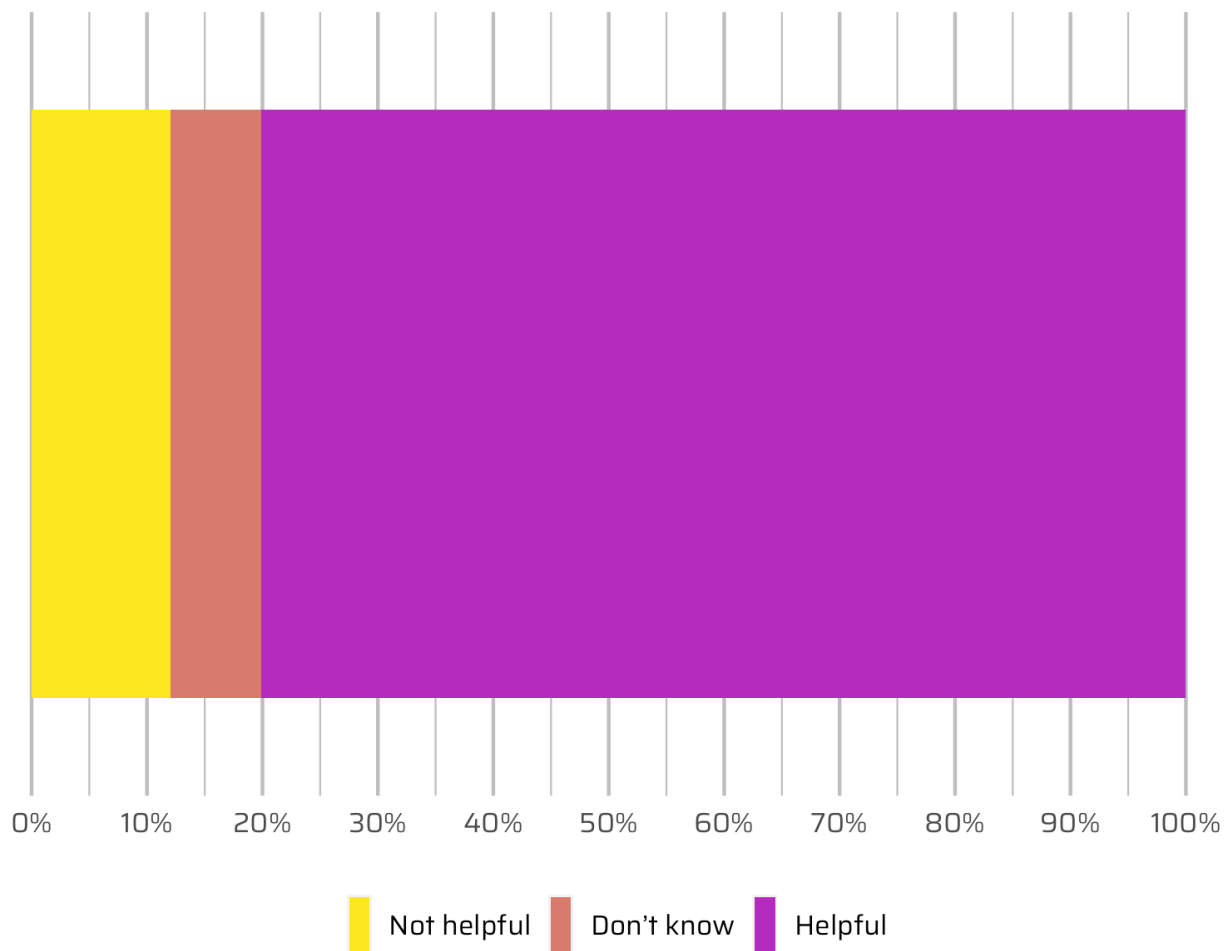


Figure 49: Helpfulness of medical appointments.

Table 49: Helpfulness of medical appointments.

Helpfulness	Observations	Percentage
Helpful	213	80
Don't know	21	8
Not helpful	32	12

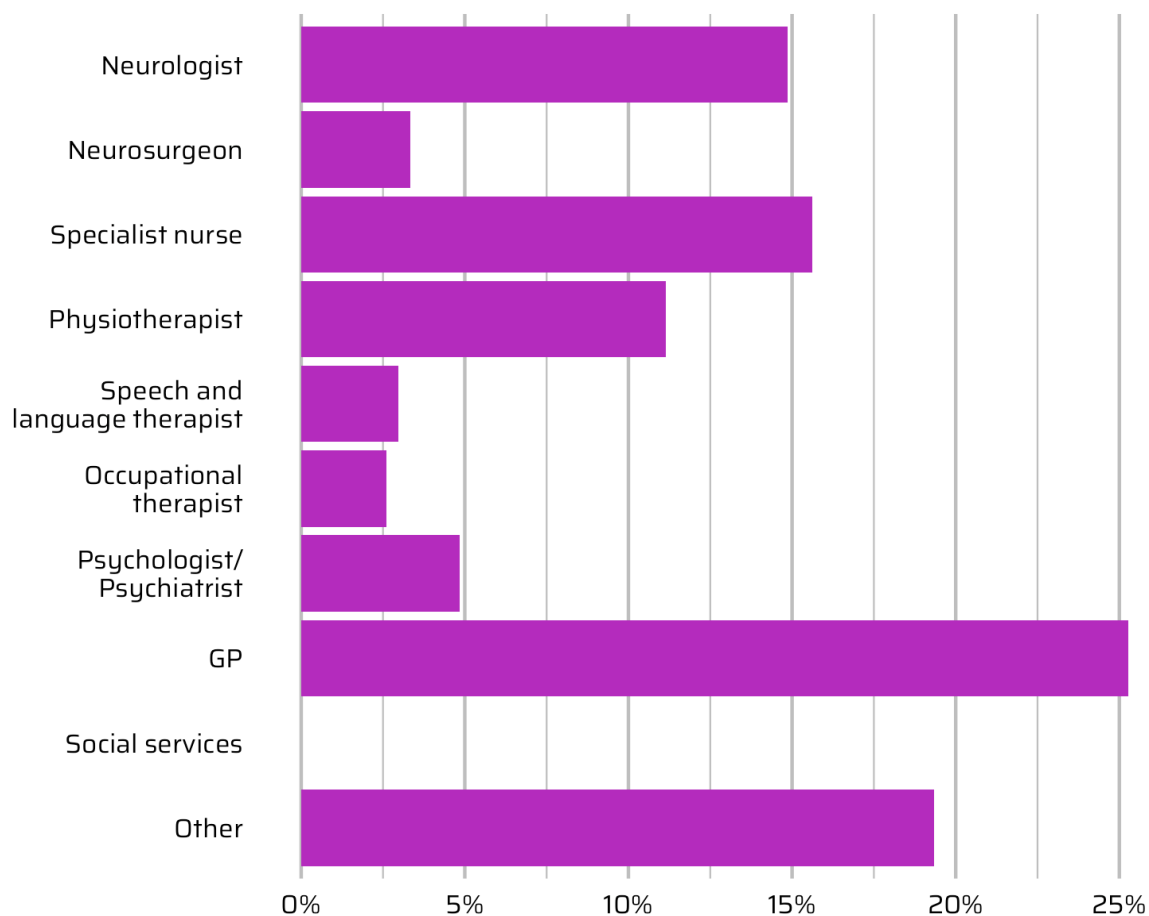


Figure 50: Type of appointment.

Table 50: Type of medical appointment.

Specialty	Observations	Percentage
Neurologist	40	15
Neurosurgeon	9	3
Specialist nurse	42	16
Physiotherapist	30	11
Speech and language therapist	8	3
Occupational therapist	7	3
Psychologist/Psychiatrist	13	5
GP	68	25
Social services	0	0
Other	52	19

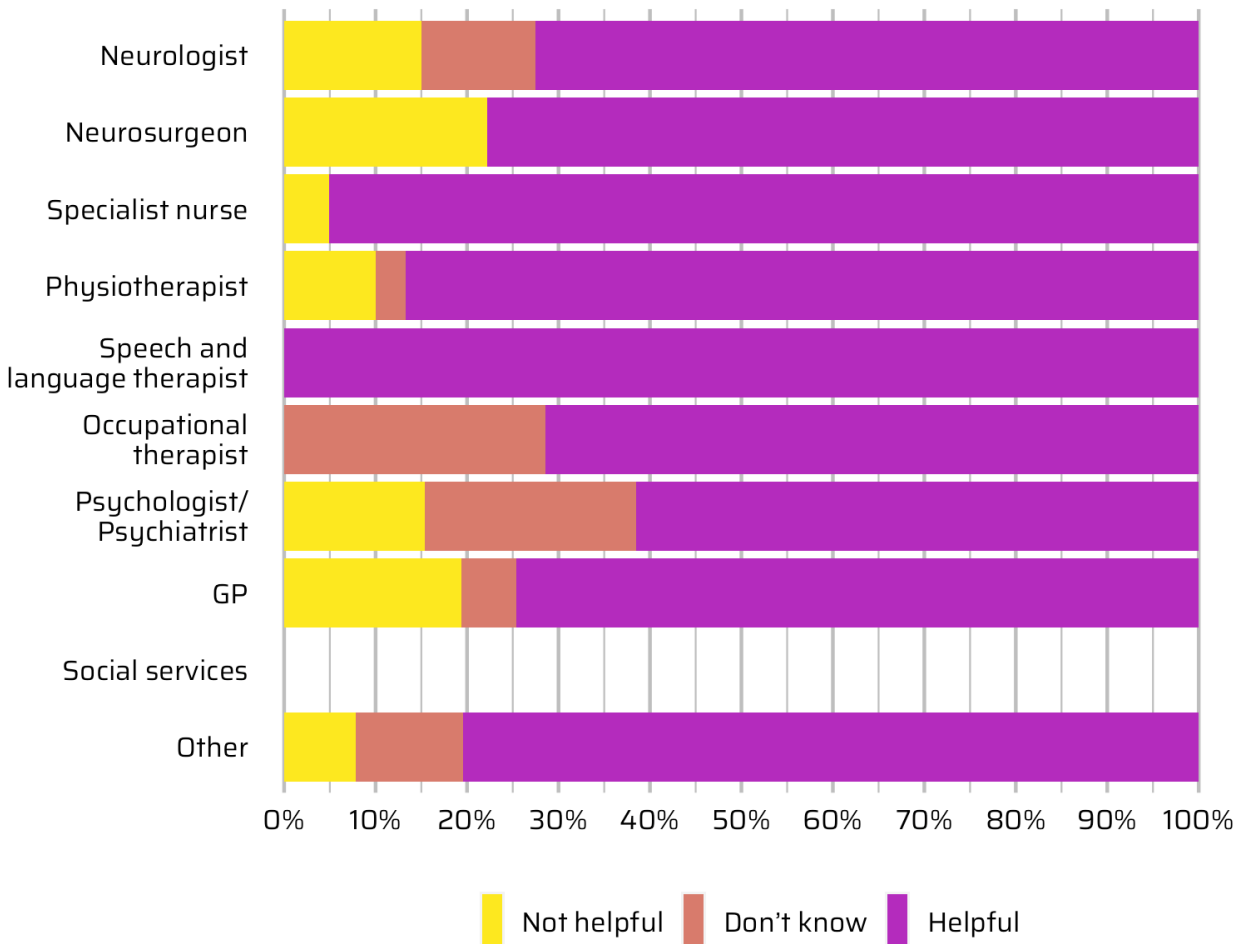


Figure 51: Helpfulness of appointment by specialty.

Table 51: Helpfulness of appointment by specialty.

Specialty	Helpfulness	Observations	Percentage
Neurologist	Helpful	29	72
Neurologist	Don't know	5	12
Neurologist	Not helpful	6	15
Neurosurgeon	Helpful	7	78
Neurosurgeon	Don't know	0	0
Neurosurgeon	Not helpful	2	22
Specialist nurse	Helpful	39	95
Specialist nurse	Don't know	0	0
Specialist nurse	Not helpful	2	5
Physiotherapist	Helpful	26	87
Physiotherapist	Don't know	1	3

Physiotherapist	Not helpful	3	10
Speech and language therapist	Helpful	8	100
Speech and language therapist	Don't know	0	0
Speech and language therapist	Not helpful	0	0
Occupational therapist	Helpful	5	71
Occupational therapist	Don't know	2	29
Occupational therapist	Not helpful	0	0
Psychologist/Psychiatrist	Helpful	8	62
Psychologist/Psychiatrist	Don't know	3	23
Psychologist/Psychiatrist	Not helpful	2	15
GP	Helpful	50	75
GP	Don't know	4	6
GP	Not helpful	13	19
Social services	Helpful	0	NaN
Social services	Don't know	0	NaN
Social services	Not helpful	0	NaN
Other	Helpful	41	80
Other	Don't know	6	12
Other	Not helpful	4	8

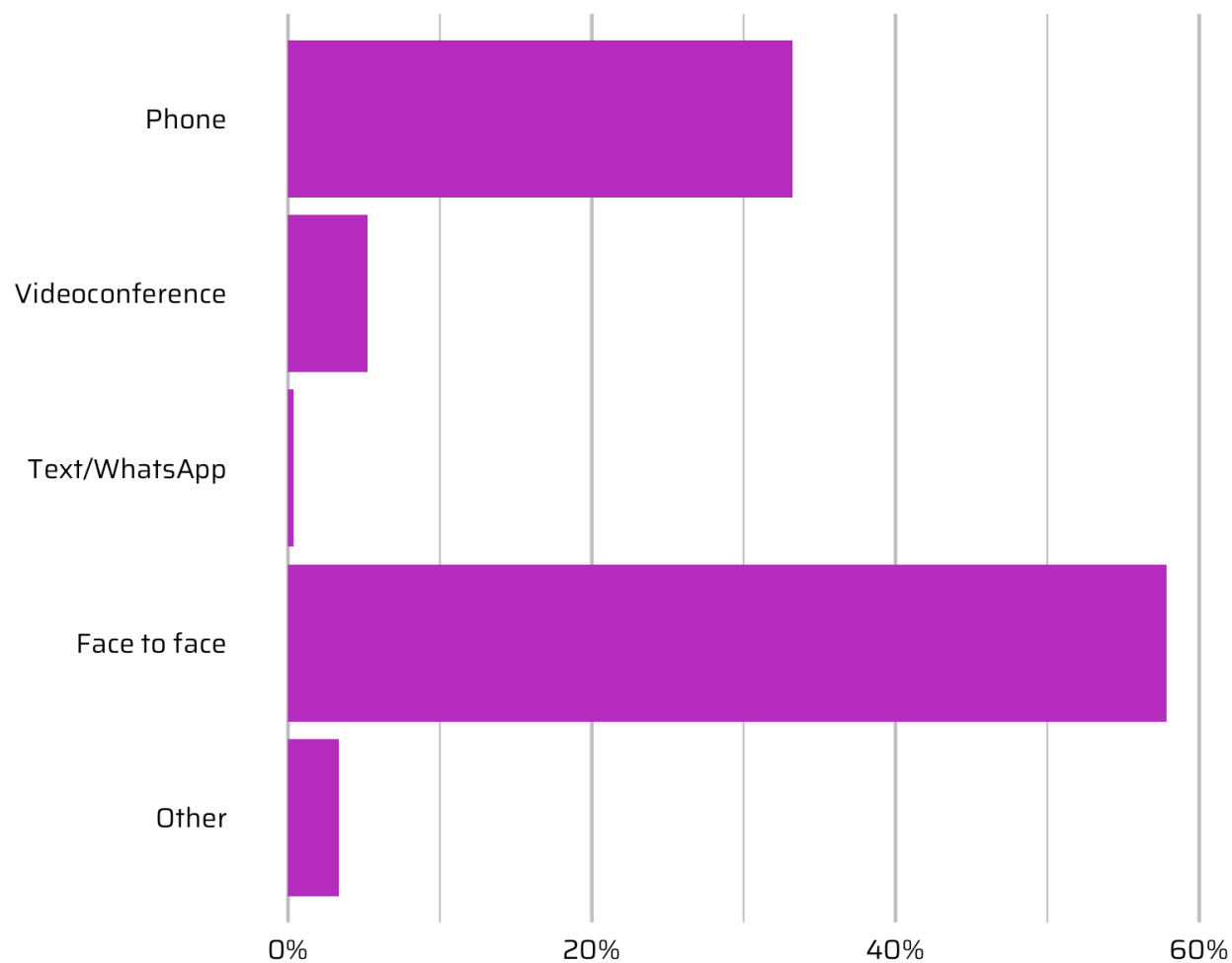


Figure 52: Mode of delivery.

Table 52: Mode of delivery.

Mode	Observations	Percentage
Phone	89	33
Videoconference	14	5
Text/WhatsApp	1	0
Face to face	155	58
Other	9	3



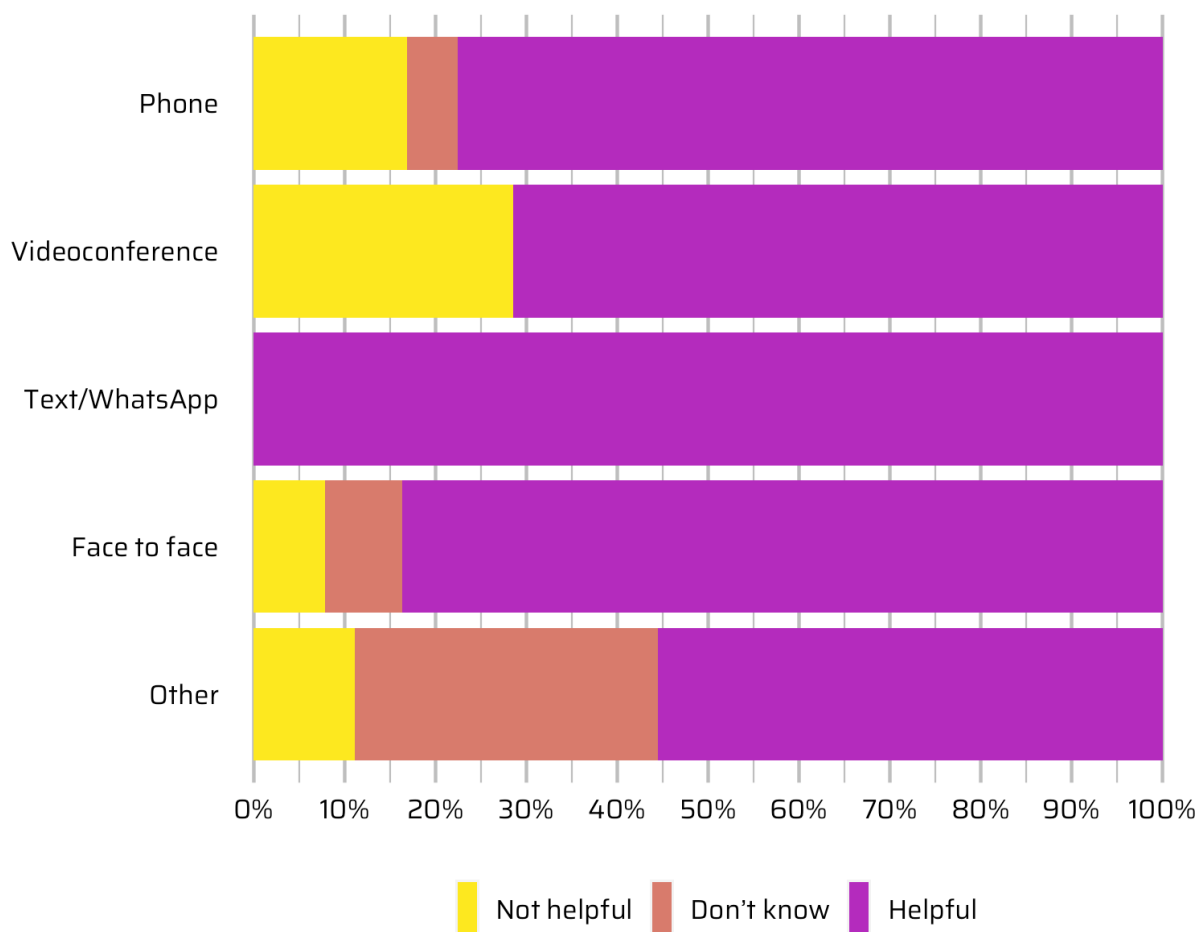


Figure 53: Helpfulness by mode of delivery.

Table 53: Helpfulness by mode of delivery.

Mode	Helpfulness	Observations	Percentage
Phone	Helpful	69	78
Phone	Don't know	5	6
Phone	Not helpful	15	17
Videoconference	Helpful	10	71
Videoconference	Don't know	0	0
Videoconference	Not helpful	4	29
Text/WhatsApp	Helpful	1	100
Text/WhatsApp	Don't know	0	0
Text/WhatsApp	Not helpful	0	0
Face to face	Helpful	128	84
Face to face	Don't know	13	8

Face to face	Not helpful	12	8
Other	Helpful	5	56
Other	Don't know	3	33
Other	Not helpful	1	11