



NeuroLifeNow

Brain & Spine
Foundation



THE
NEUROLOGICAL
ALLIANCE

Brain & Spine Foundation registered charity no. 1098528

NEUROLIFENOW

Analysis Report

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May and June 2022 Survey Responses

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“After 18 months of seeing specialist doctors and having had MRI and CT scans (private and NHS), finally I have confirmed spinal CSF leak. I’m still waiting for epidural blood patch from January 2022 – it’s been months and still don’t have a date. My condition is deteriorating, every month I have more symptoms with most of my life I spent in bed, in pain.” – NeuroLifeNow survey respondent

Foreword

We’re pleased to share this report with you after a short hiatus over the summer. And what a summer it was – we have experienced significant political, economic turmoil, with NHS services ‘bracing’ for winter.

Despite this, we have used this time to review NeuroLifeNow, with a view to developing the platform to ensure it meets your needs and is valuable to you. We tested a new survey design and recruited more than 40 people affected by neurological conditions to help shape the future of the platform. We are delighted to say that even with a few small tweaks, we have increased the number of people responding to the survey and have received good feedback so far.

In May and June, you told us that you continue to face significant issues in accessing support. Overall, there was one word that came up again and again – **waiting**. Waiting for your GP to refer you to specialist services. Waiting for a scan. Waiting for answers.

“I received a letter saying that physiotherapy have received a referral from my neurologist but that they can’t book anything for me due to the waiting list being too long. I now have to wait for them to contact me at a later date.”

As of August 2022, more than 280,000 people were waiting for an NHS neurology appointment or NHS neurosurgery. More than 10,000 people have waited more than a year – all the while experiencing changes to their condition, unanswered questions and huge levels of anxiety.

There has been a push across the UK to address long waits. But, without the right investment in our workforce, in the right diagnostics and support, the right support after hospital and the right community care, people will continue to wait, and their health may deteriorate as a result.

The new Government has a choice. They can choose to back the 1 in 6 living with a neurological condition and set out their plans to address these challenges. More than 13,500 people already have shown their support by signing the [Back the 1 in 6 petition](#) and it is time Government's across the UK did too - people affected by neurological conditions have waited too long.

You are not alone. The Brain and Spine Foundation's free, national Helpline provides a trusted and safe space where you can seek professional support and guidance from neuroscience nurses. Call **0808 808 1000** (Mon-Thurs, 9am - 4pm) or email helpline@brainandspine.org.uk.

Thank you,

Marc Smith, CEO Brain and Spine Foundation

Georgina Carr, CEO Neurological Alliance (England)

Background

There are more people in the UK living with a neurological condition than cancer, heart disease or diabetes. Change is needed urgently because the current system is under-funded, inadequately resourced, and fails individuals and families too often. NeuroLifeNow is a platform designed to support people with neurological conditions to share experiences of their care. Insights are shared with NHS Commissioners, UK Governments and clinicians to influence how neurological services are delivered and to drive positive change. The data in this report is derived from responses received between 1 May – 30 June 2022. The full questionnaire and data tables are available in the appendices.

Key findings

- 278 people shared their experiences in May and June, with 74% female respondents and 26% male.
- 68 different neurological conditions and symptoms were represented in the survey. Dystonia, multiple sclerosis, and functional neurological disorder (FND) were the top three represented. 71% of respondents had at least one other non-neurological condition.
- 58% of respondents said their mental health needs weren't being met or were only met to a small extent. Those who experienced delays or cancellations to care were more likely to say this (72%).
- 1 in 10 people (13%) experienced delays to their care in the May and June survey.
- 64% of respondents told us they felt anxious or hopeless.
- Overall, 73% of the medical appointments evaluated were considered helpful.
- 56% of people said their experience of care was good or very good in the past 8 weeks – a increase from 50% of respondents who said this in March.

Qualitative data

We asked you about your experience of health and care services in this survey. We have created a word cloud graphic below to share with you the words most commonly used, demonstrating the shared experience of our community.



Themes

Overall, 7 themes have emerged:

Theme 1: Frustration with the services

You expressed your dissatisfaction or frustration towards the services accessed (or tried to access). Reasons cited are: long waiting time, lack of support, misdiagnosis/misunderstandings, and cancellations. One also expressed their concerns towards burnt out healthcare workers.

Here are your words:

"I went in to hospital for an aneurysm embolization. I was left sitting in corridor outside the ward I was supposed to be going into for 2 hours even though they knew I was waiting - then told me they had been looking for me when I was sitting outside the ward all along. It was shocking as I was very nervous to begin with as the previous year I had a subarachnoid hemorrhage (SAH) after an embolization went wrong."

"Waiting times to see specialist consultants and services are so long or only in certain areas. This means that conditions are left untreated and things worsen and other complications occur. Also, many health professionals have inadequate knowledge or have never heard of a lot of conditions. I am awaiting treatment for OCD which has taken over my life and have been told at least 7/8 months wait..."

"I have no relatives, at risk of AD. I couldn't stand up for myself and have now lost confidence in the NHS. No idea what is happening to me as nobody is monitoring me for the myelopathy side nor risk of cauda equina."

Theme 2: Struggling to cope

Many of you expressed you are not able to cope due to your condition(s). Issues reported include sleeping problems, mobility problems, mental health problems, self-care, financial problems, and loneliness.

Your words:

"I am still struggling to adjust to my life, I struggle most days and need to rest. I have forget things and rely on my husband and daughter."

"Poor sleep has been a constant problem since my diagnosis but over the past 4 months I have been having too many nights with no sleep at all."

"I am having to use an emergency care agency as my old carers no longer had capacity and as a result although I have a wash every day, they are not able to give me a shower due to capacity. It has now been 13 weeks since I last had a shower."

Theme 3: Relieved by the services

Some of you expressed optimism, relief and appreciation towards the services you accessed.

Your words:

"Things seem to be moving nice and quickly in the last 8 weeks. I've seen two specialists, two to go before I get a decision on whether or not I can have a nerve stimulator put in my back. Feeling very optimistic."

"I had to call ambulance twice, because I fell and can't get up by myself, and both times they arrived reasonably quickly and were very helpful."

"I have a regular checkup as an outpatient and the care I receive is always excellent"

Theme 4: Sought help elsewhere

Due to limited services you could access (long waiting time, cancellations etc), a few of you sought help elsewhere such as the internet or private services.

Your words:

"I had a full spine private MRI, that we paid for in desperation to confirm why I was feeling so much worse..."

"...by now I had sort of re-trained my brain mainly with short walks and a few exercises from the internet."

"I am in private appointments all year. I have NO neurological/neurosurgical/pain support in Northern Ireland."

Theme 5: Patient/public involvement

One of you shared taking an active role in working with organisations to increase awareness and make sure the voices of the patients are heard:

"I also was invited to the DHSC Select Committee to offer my perspectives on NHS workforce experiences. I have been working with WHO on developing the NCD 'framework'. I do a lot of patient and public involvement work with many organisations."

Theme 6: COVID

Some of you continue to report COVID-related issues, such as the negative impact of mask-wearing and virtual appointments.

Your words:

"I have been attempting for years to get my bilateral sensorineural hearing loss flagged up on my medical notes so that clinicians are immediately aware that I have hearing impairment, use hearing aids and invariably will need to lipread. This was only implemented a few weeks ago after I mentioned to one of my neuro team how frustrating and stressful it is not to be able to hear my name being called, having to communicate via screens/masks/phones when it is often impossible to hear/interpret, and I make frequent mistakes or mishear important information. Rarely are my requests for lipreading/accessibility heeded, or if they are, it's only for a few moments until the person forgets – do I need to get a t-shirt with it emblazoned on?"

"I was sent home when Covid-19 was rampant in the hospital. After that I was sent for an appointment for their 'balance clinic' which got cancelled due to Covid so approx. 4 months later was seen at the clinic."

"Certainly, prefer face to face appointments. Technology I find incredibly confusing sometimes."

Theme 7: Path to recovery

A few of you shared you are recovering (e.g. from accidents), or are trying to be more independent.

"Trying to get a DVLA medical to try and get my driving license back after seizures."

"Dislocated shoulder after a fall. A&E for 12 hours. Recovering slowly."

"I am also working closely with my GP trying to get my sleep and pain improved."

Quantitative data

Extent Mental Health Needs Met

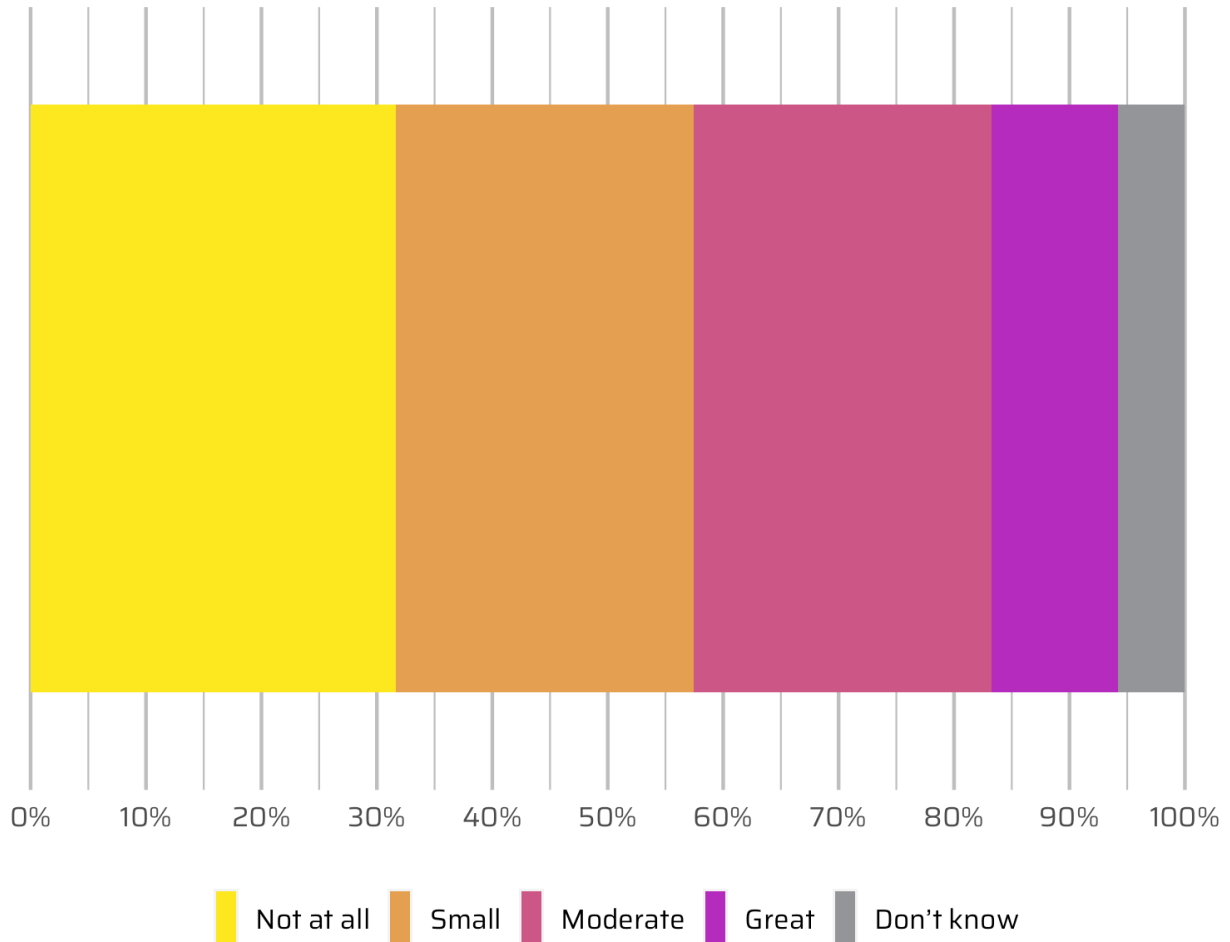


Figure 1: Extent mental health needs of respondents are being met.

Table 1: Extent mental health needs of respondents are being met.

Extent	Respondents	Percentage
Great	30	11
Moderate	71	26
Small	71	26
Not at all	87	32
Don't know	16	6

Gender: Extent Mental Health Needs Met

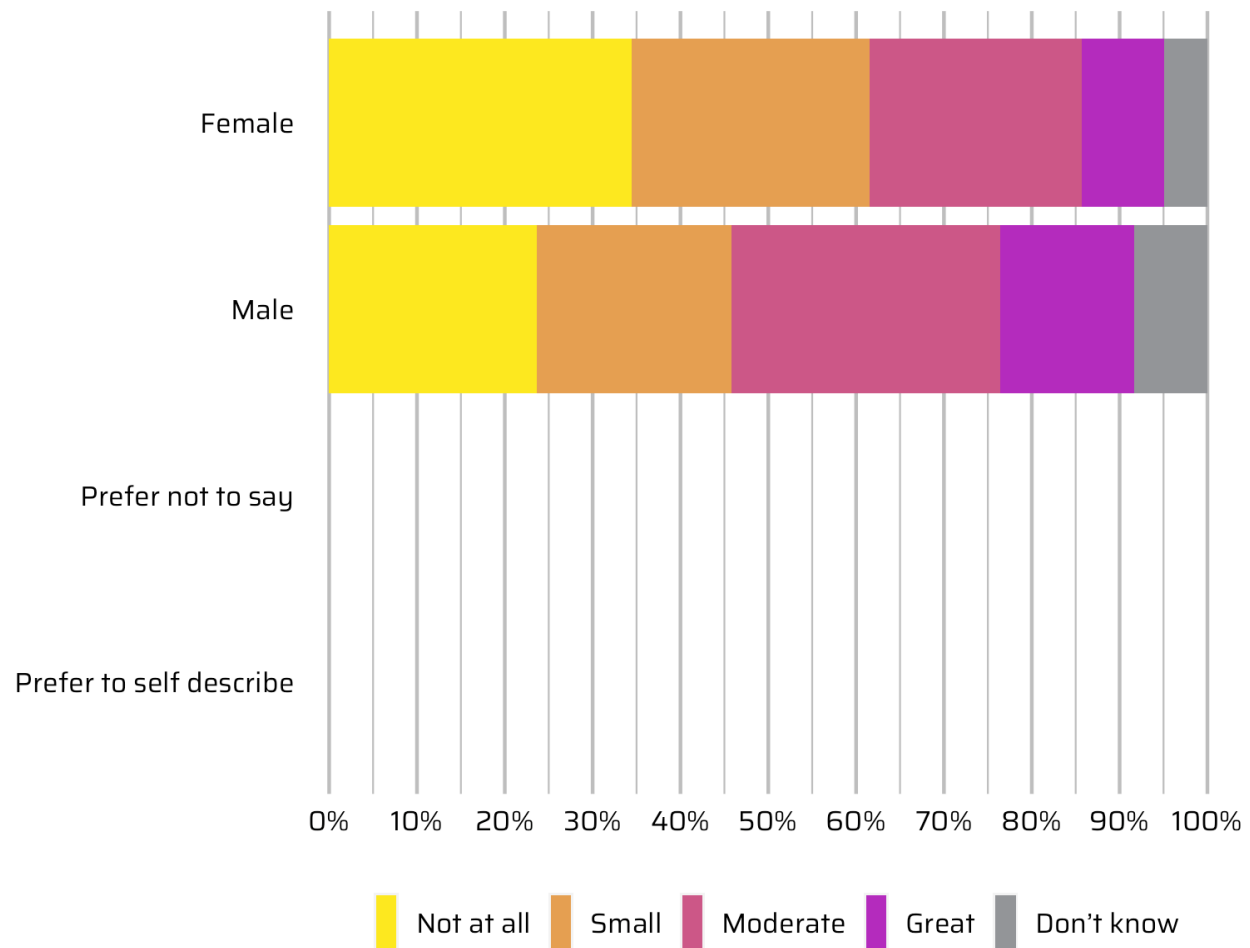


Figure 2: Extent mental health needs of respondents are being met by gender.

Table 2: Extent mental health needs of respondents are being met by gender.

Gender	Extent	Respondents	Percentage
Female	Great	19	9
Female	Moderate	49	24
Female	Small	55	27
Female	Not at all	70	34
Female	Don't know	10	5
Male	Great	11	15
Male	Moderate	22	31
Male	Small	16	22

Gender	Extent	Respondents	Percentage
Male	Not at all	17	24
Male	Don't know	6	8
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	NaN
Prefer to self describe	Moderate	0	NaN
Prefer to self describe	Small	0	NaN
Prefer to self describe	Not at all	0	NaN
Prefer to self describe	Don't know	0	NaN

Employment Status: Extent Mental Health Needs Met

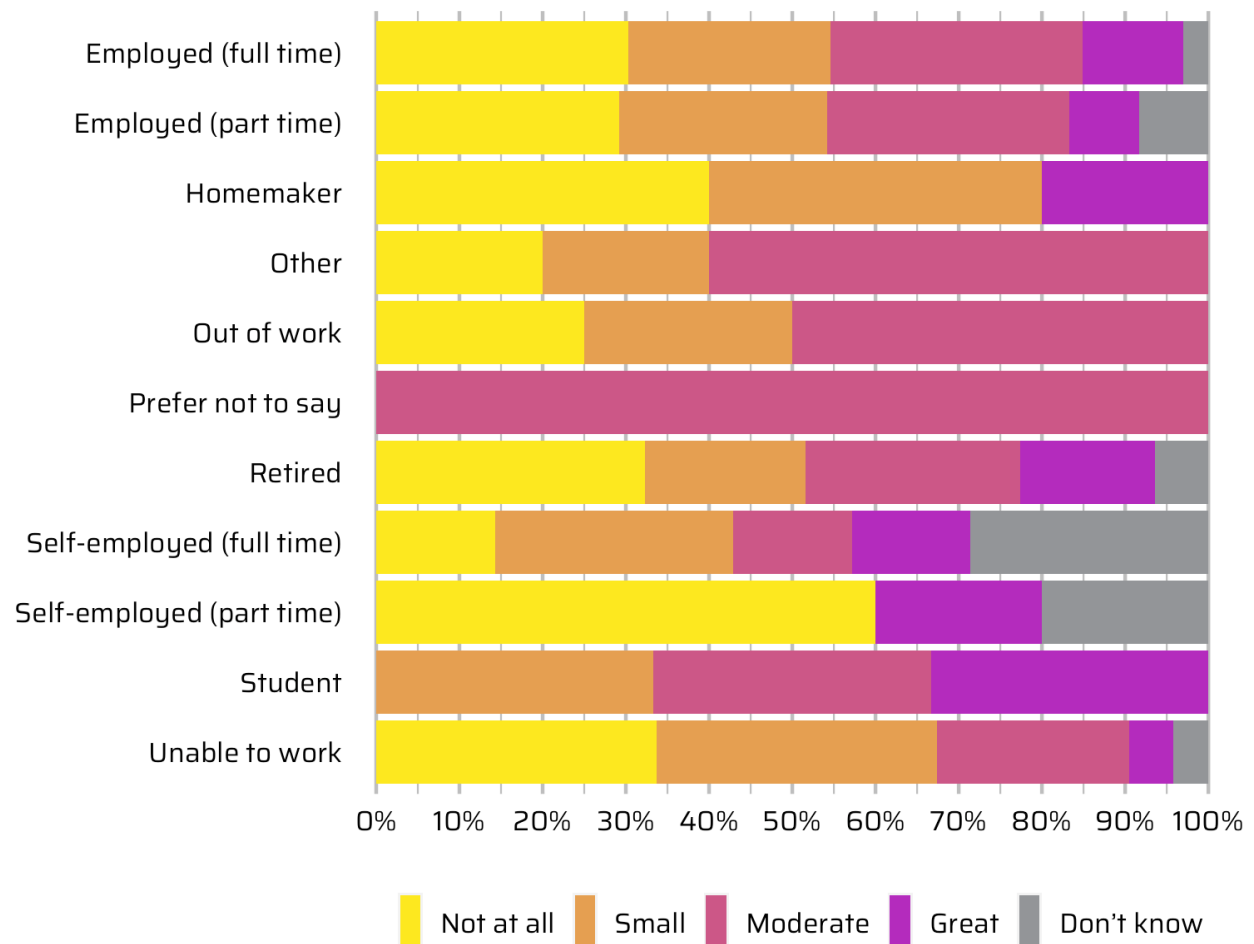


Figure 3: Extent mental health needs of respondents are being met by employment status

Table 3: Extent mental health needs of respondents are being met by employment status

Employment Status	Extent	Respondents	Percentage
Employed (full time)	Great	4	12
Employed (full time)	Moderate	10	30
Employed (full time)	Small	8	24
Employed (full time)	Not at all	10	30
Employed (full time)	Don't know	1	3
Employed (part time)	Great	2	8

Employment Status	Extent	Respondents	Percentage
Employed (part time)	Moderate	7	29
Employed (part time)	Small	6	25
Employed (part time)	Not at all	7	29
Employed (part time)	Don't know	2	8
Homemaker	Great	1	20
Homemaker	Moderate	0	0
Homemaker	Small	2	40
Homemaker	Not at all	2	40
Homemaker	Don't know	0	0
Other	Great	0	0
Other	Moderate	3	60
Other	Small	1	20
Other	Not at all	1	20
Other	Don't know	0	0
Out of work	Great	0	0
Out of work	Moderate	2	50
Out of work	Small	1	25
Out of work	Not at all	1	25
Out of work	Don't know	0	0
Prefer not to say	Great	0	0
Prefer not to say	Moderate	1	100
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
Retired	Great	15	16
Retired	Moderate	24	26
Retired	Small	18	19
Retired	Not at all	30	32
Retired	Don't know	6	6
Self-employed (full time)	Great	1	14
Self-employed (full time)	Moderate	1	14
Self-employed (full time)	Small	2	29
Self-employed (full time)	Not at all	1	14

Employment Status	Extent	Respondents	Percentage
Self-employed (full time)	Don't know	2	29
Self-employed (part time)	Great	1	20
Self-employed (part time)	Moderate	0	0
Self-employed (part time)	Small	0	0
Self-employed (part time)	Not at all	3	60
Self-employed (part time)	Don't know	1	20
Student	Great	1	33
Student	Moderate	1	33
Student	Small	1	33
Student	Not at all	0	0
Student	Don't know	0	0
Unable to work	Great	5	5
Unable to work	Moderate	22	23
Unable to work	Small	32	34
Unable to work	Not at all	32	34
Unable to work	Don't know	4	4

Number of Dependents: Extent Mental Health Needs Met

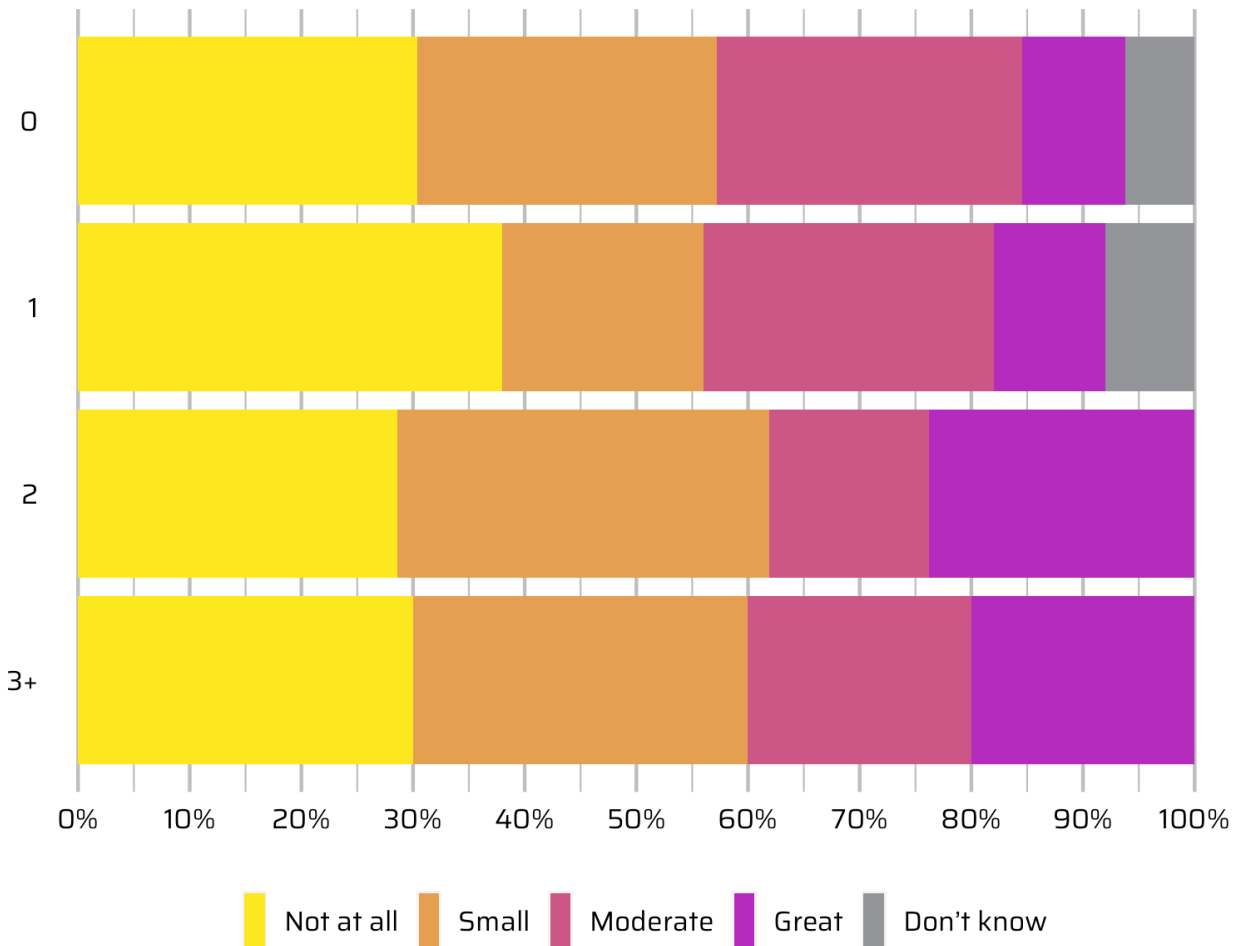


Figure 4: Extent mental health needs of respondents are being met by number of dependents.

Table 4: Extent mental health needs of respondents are being met by number of dependents.

Dependents	Extent	Respondents	Percentage
0	Great	18	9
0	Moderate	53	27
0	Small	52	27
0	Not at all	59	30
0	Don't know	12	6
1	Great	5	10

Dependents	Extent	Respondents	Percentage
1	Moderate	13	26
1	Small	9	18
1	Not at all	19	38
1	Don't know	4	8
2	Great	5	24
2	Moderate	3	14
2	Small	7	33
2	Not at all	6	29
2	Don't know	0	0
3+	Great	2	20
3+	Moderate	2	20
3+	Small	3	30
3+	Not at all	3	30
3+	Don't know	0	0

Anxious or Hopeless Feeling: Extent Mental Health Needs Met

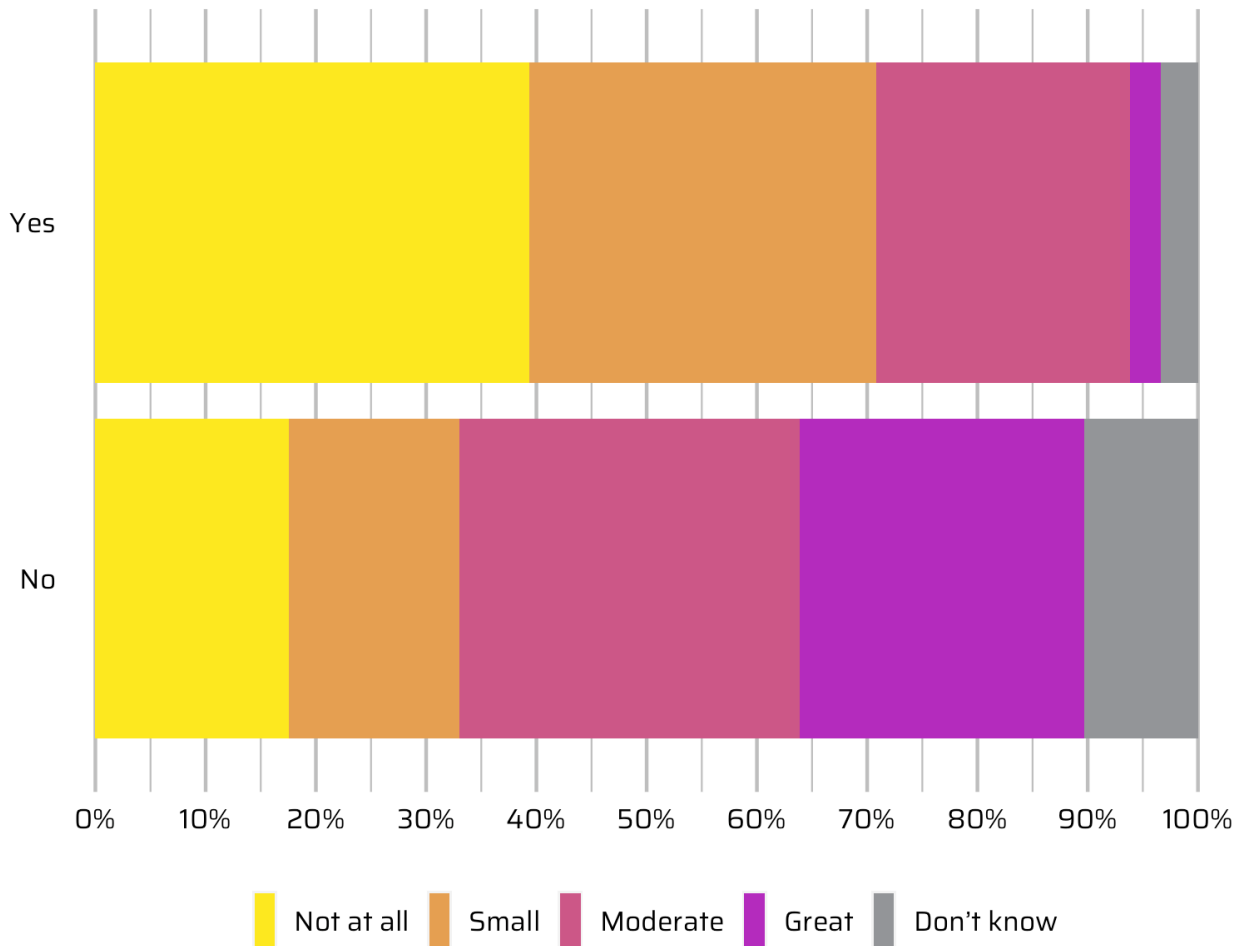


Figure 5: Extent mental health needs of respondents are being met by feeling anxious or hopeless .

Table 5: Extent mental health needs of respondents are being met by feeling anxious or hopeless ..

Anxious or Hopeless	Extent	Respondents	Percentage
Yes	Great	5	3
Yes	Moderate	41	23
Yes	Small	56	31
Yes	Not at all	70	39
Yes	Don't know	6	3
No	Great	25	26

Anxious or Hopeless	Extent	Respondents	Percentage
No	Moderate	30	31
No	Small	15	15
No	Not at all	17	18
No	Don't know	10	10

Cancellation or Delay of Care : Extent Mental Health Needs Met

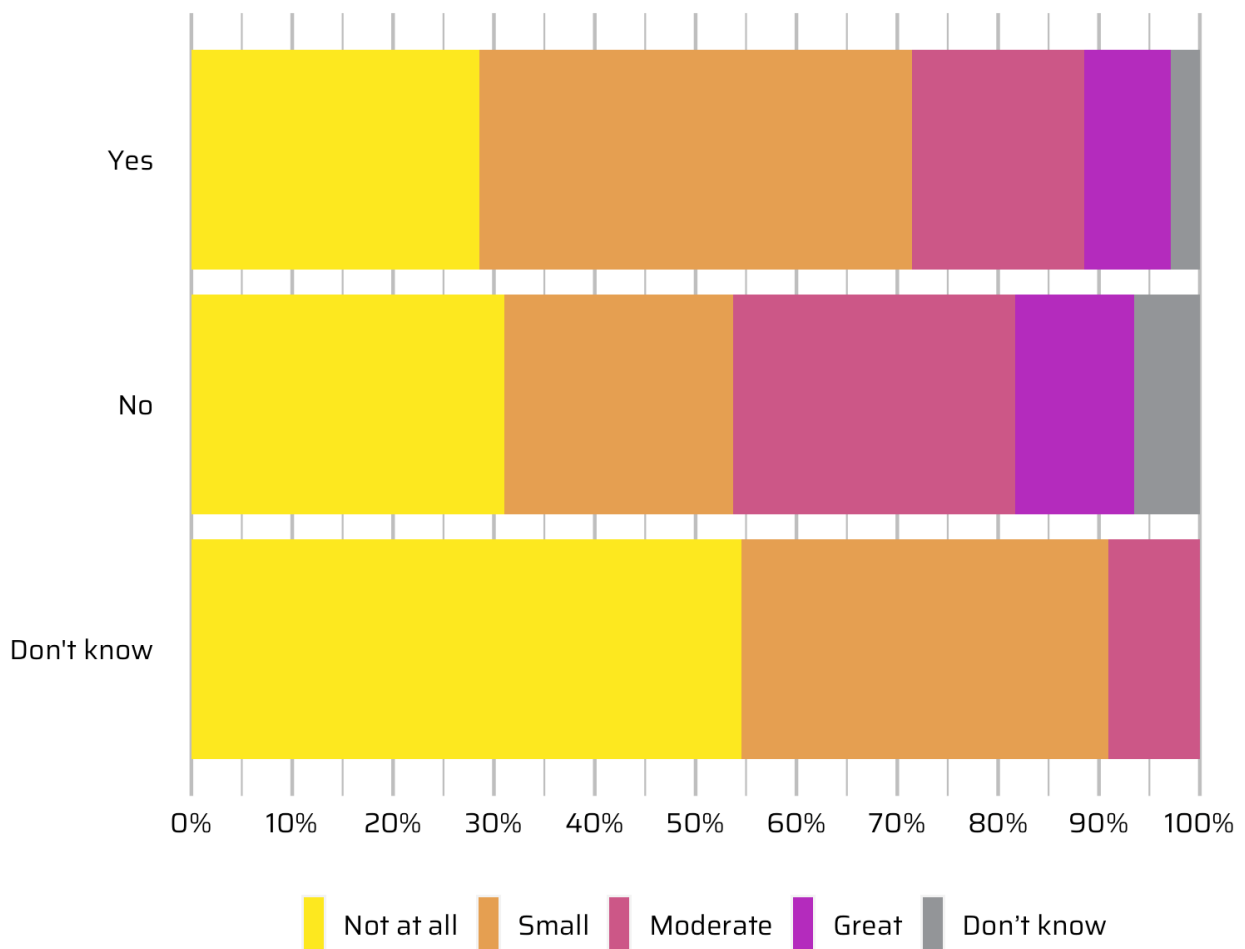


Figure 6: Extent mental health needs of respondents are being met by cancellation or delays of care.

Table 6: Extent mental health needs of respondents are being met by cancellation or delays of care.

Cancellation	Extent	Respondents	Percentage
Yes	Great	3	9
Yes	Moderate	6	17
Yes	Small	15	43
Yes	Not at all	10	29
Yes	Don't know	1	3
No	Great	27	12
No	Moderate	64	28
No	Small	52	23
No	Not at all	71	31
No	Don't know	15	7
Don't know	Great	0	0
Don't know	Moderate	1	9
Don't know	Small	4	36
Don't know	Not at all	6	55
Don't know	Don't know	0	0

Financial Status: Extent Mental Health Needs Met

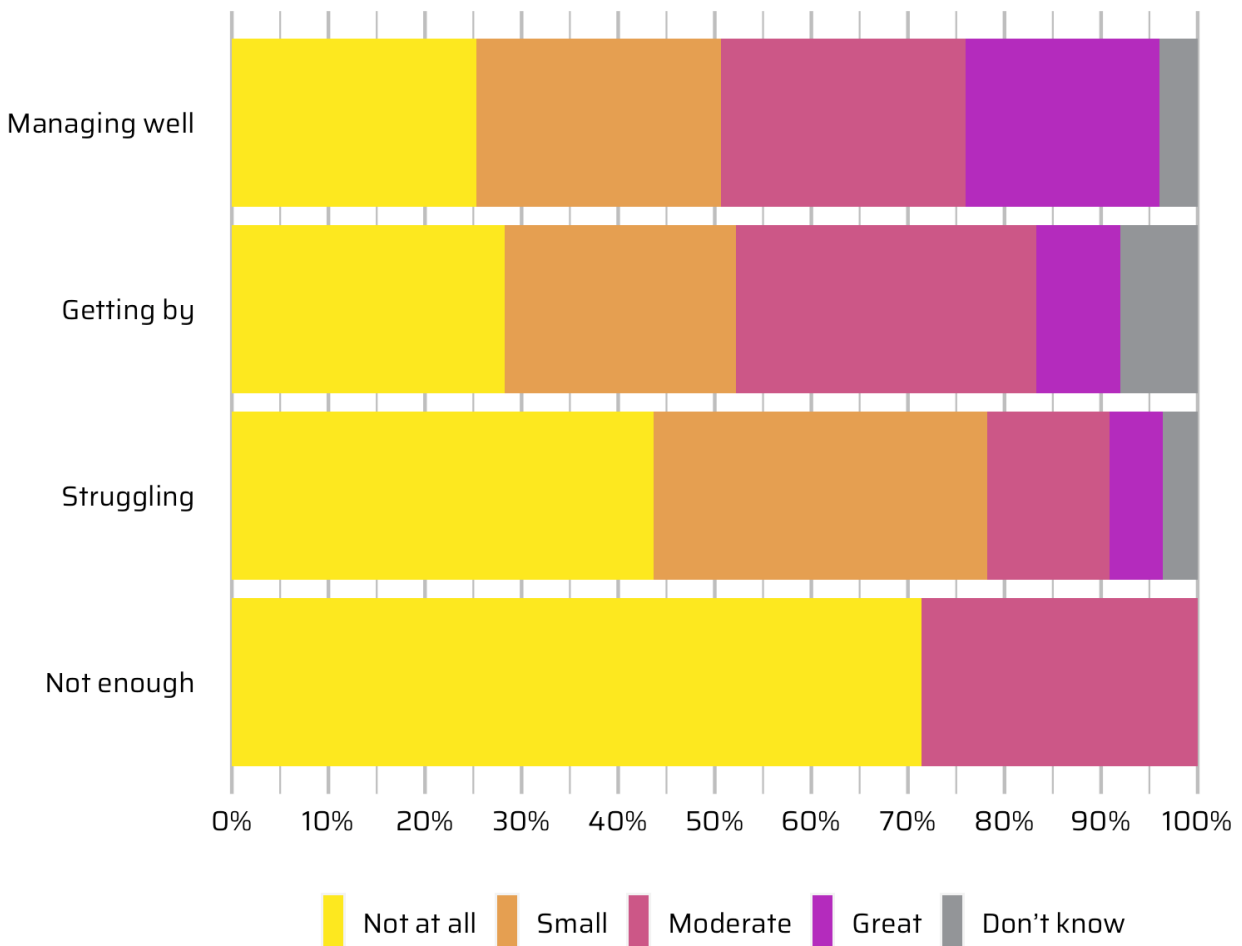


Figure 7: Extent mental health needs of respondents are being met by cancellation or delays of care.

Table 7: Extent mental health needs of respondents are being met by cancellation or delays of care.

Financial Status	Extent	Respondents	Percentage
Managing well	Great	15	20
Managing well	Moderate	19	25
Managing well	Small	19	25
Managing well	Not at all	19	25
Managing well	Don't know	3	4
Getting by	Great	12	9

Financial Status	Extent	Respondents	Percentage
Getting by	Moderate	43	31
Getting by	Small	33	24
Getting by	Not at all	39	28
Getting by	Don't know	11	8
Struggling	Great	3	5
Struggling	Moderate	7	13
Struggling	Small	19	35
Struggling	Not at all	24	44
Struggling	Don't know	2	4
Not enough	Great	0	0
Not enough	Moderate	2	29
Not enough	Small	0	0
Not enough	Not at all	5	71
Not enough	Don't know	0	0

Age: Extent Mental Health Needs Met

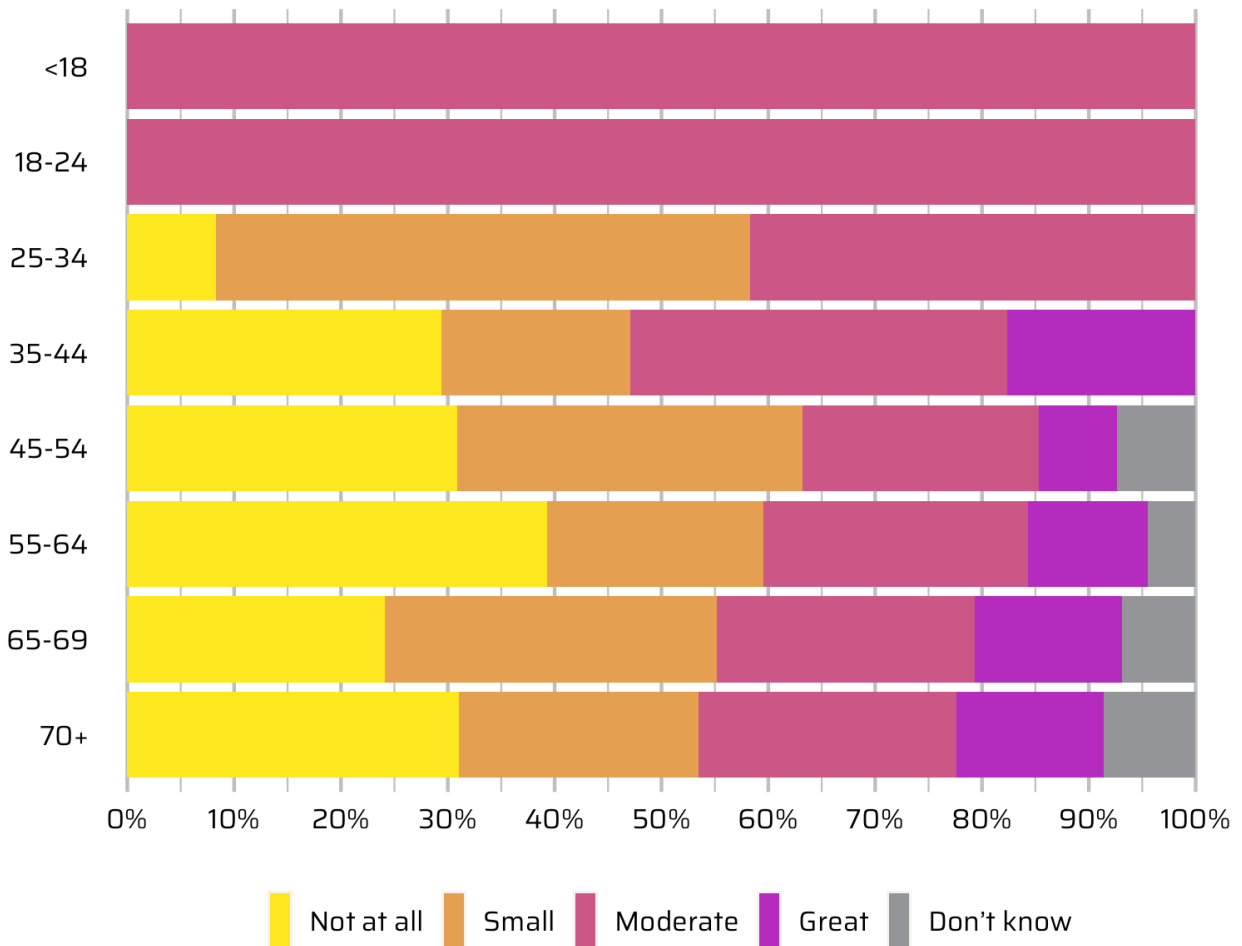


Figure 8: Extent mental health needs of respondents are being met by age.

Table 8: Extent mental health needs of respondents are being met by age.

Age	Extent	Respondents	Percentage
<18	Great	0	0
<18	Moderate	1	100
<18	Small	0	0
<18	Not at all	0	0
<18	Don't know	0	0
18-24	Great	0	0
18-24	Moderate	1	100
18-24	Small	0	0

Age	Extent	Respondents	Percentage
18-24	Not at all	0	0
18-24	Don't know	0	0
25-34	Great	0	0
25-34	Moderate	5	42
25-34	Small	6	50
25-34	Not at all	1	8
25-34	Don't know	0	0
35-44	Great	3	18
35-44	Moderate	6	35
35-44	Small	3	18
35-44	Not at all	5	29
35-44	Don't know	0	0
45-54	Great	5	7
45-54	Moderate	15	22
45-54	Small	22	32
45-54	Not at all	21	31
45-54	Don't know	5	7
55-64	Great	10	11
55-64	Moderate	22	25
55-64	Small	18	20
55-64	Not at all	35	39
55-64	Don't know	4	4
65-69	Great	4	14
65-69	Moderate	7	24
65-69	Small	9	31
65-69	Not at all	7	24
65-69	Don't know	2	7
70+	Great	8	14
70+	Moderate	14	24
70+	Small	13	22
70+	Not at all	18	31
70+	Don't know	5	9

Anxious or Hopeless Feeling

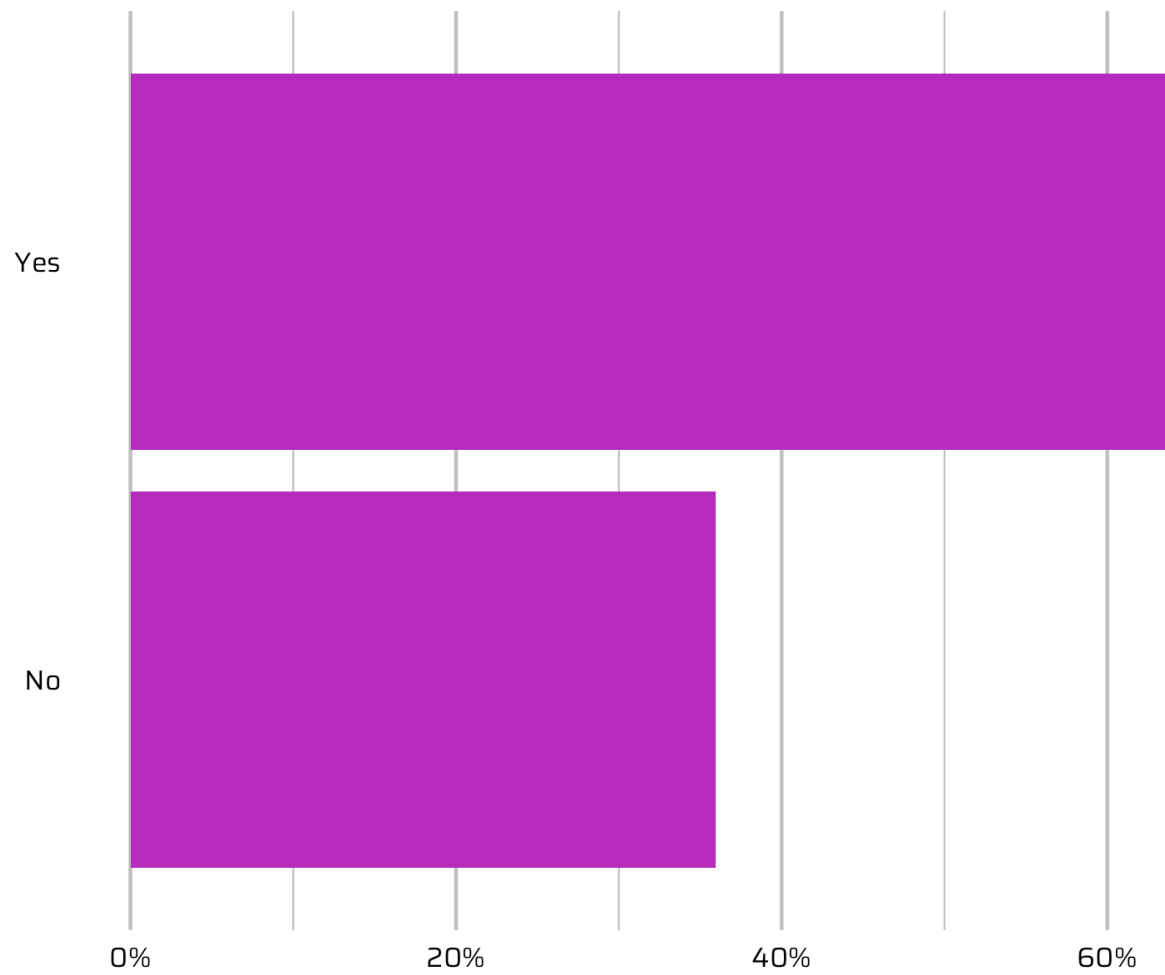


Figure 9: Respondents reporting feeling anxious or hopeless.

Table 9: Respondents reporting feeling anxious or hopeless.

Anxious or Hopeless	Respondents	Percentage
Yes	178	64
No	100	36

Cancellation or Delay of Care: Anxious or Hopeless Feeling

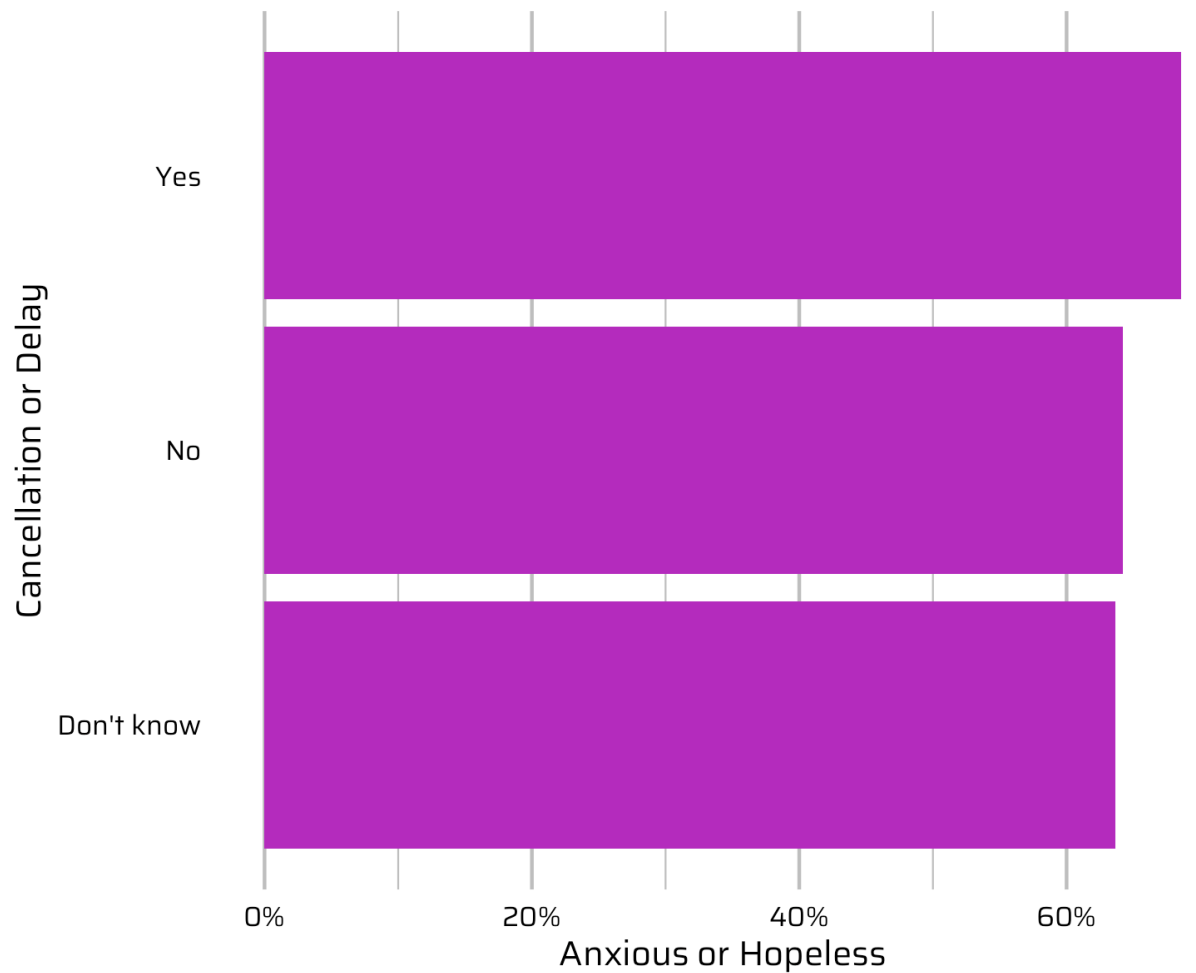


Figure 10: Respondents reporting feeling anxious or hopeless by cancellation or delays of care.

Table 10: Respondents reporting feeling anxious or hopeless by cancellation or delays of care.

Cancellation	Anxious or Hopeless	Respondents	Percentage
Yes	Yes	24	69
Yes	No	11	31
No	Yes	147	64
No	No	82	36
Don't know	Yes	7	64
Don't know	No	4	36

Cancellation Anxious or Hopeless Respondents Percentage

Employment Status: Anxious or Hopeless Feeling

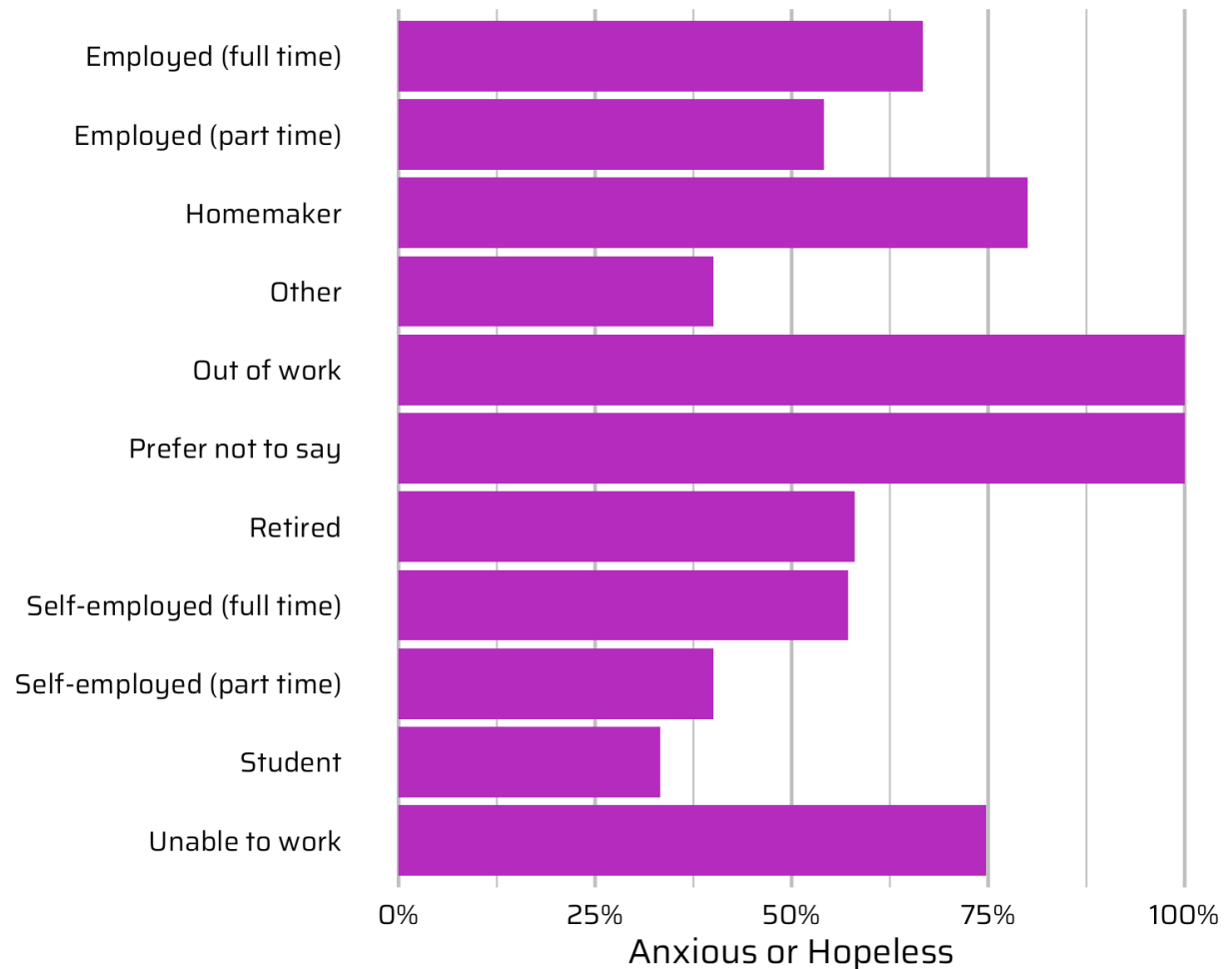


Figure 11: Respondents reporting feeling anxious or hopeless by employment status.

Table 11: Respondents reporting feeling anxious or hopeless by employment status.

Employment Status	Anxious or Hopeless	Respondents	Percentage
Employed (full time)	Yes	22	67
Employed (full time)	No	11	33
Employed (part time)	Yes	13	54
Employed (part time)	No	11	46
Homemaker	Yes	4	80

Employment Status	Anxious or Hopeless	Respondents	Percentage
Homemaker	No	1	20
Other	Yes	2	40
Other	No	3	60
Out of work	Yes	4	100
Out of work	No	0	0
Prefer not to say	Yes	1	100
Prefer not to say	No	0	0
Retired	Yes	54	58
Retired	No	39	42
Self-employed (full time)	Yes	4	57
Self-employed (full time)	No	3	43
Self-employed (part time)	Yes	2	40
Self-employed (part time)	No	3	60
Student	Yes	1	33
Student	No	2	67
Unable to work	Yes	71	75
Unable to work	No	24	25

Financial Status: Anxious or Hopeless Feeling

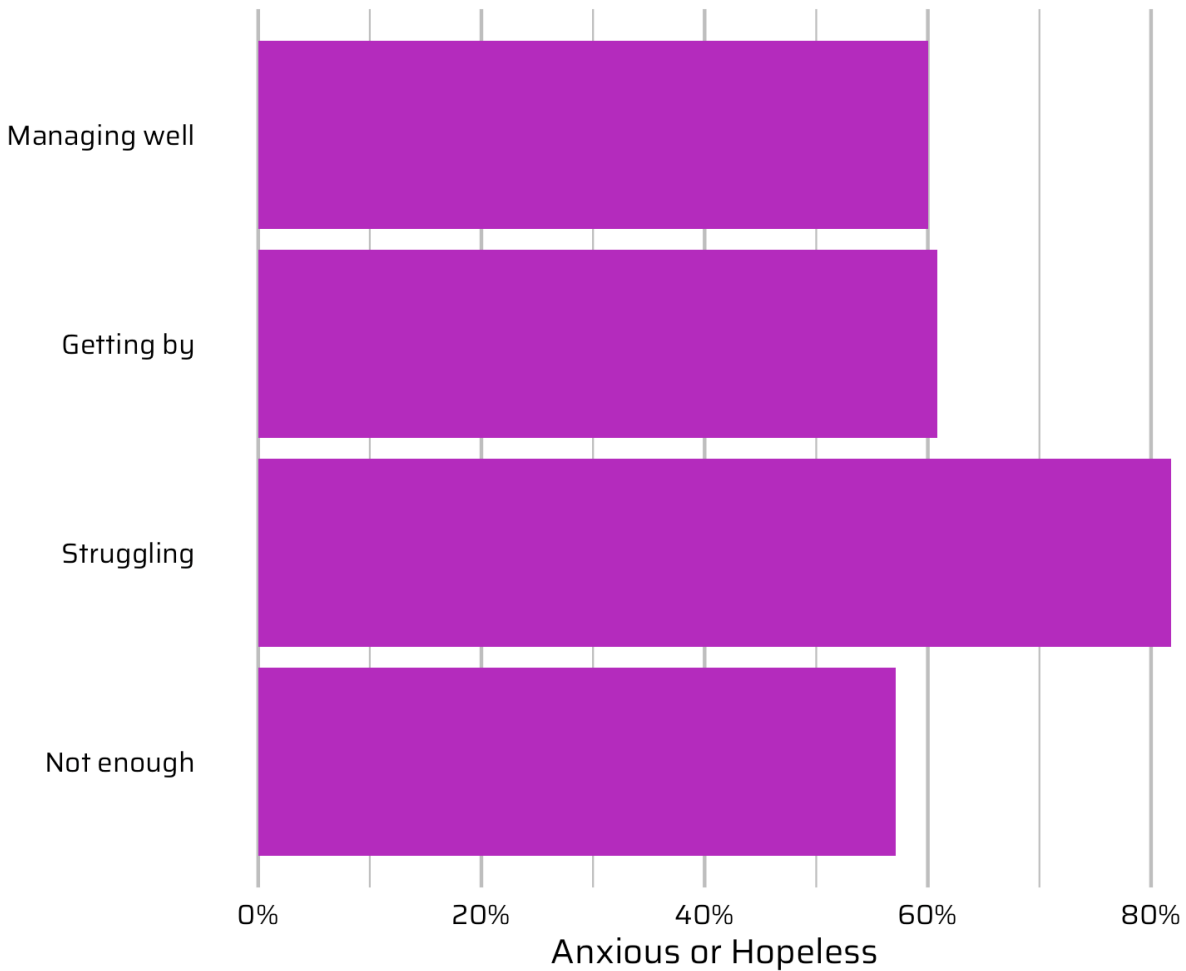


Figure 12: Respondents reporting feeling anxious or hopeless by financial status.

Table 12: Respondents reporting feeling anxious or hopeless by financial status.

Financial Status	Anxious or Hopeless	Respondents	Percentage
Managing well	Yes	45	60
Managing well	No	30	40
Getting by	Yes	84	61
Getting by	No	54	39
Struggling	Yes	45	82
Struggling	No	10	18
Not enough	Yes	4	57
Not enough	No	3	43

Frequency NHS A&E/Emergency Support Sought

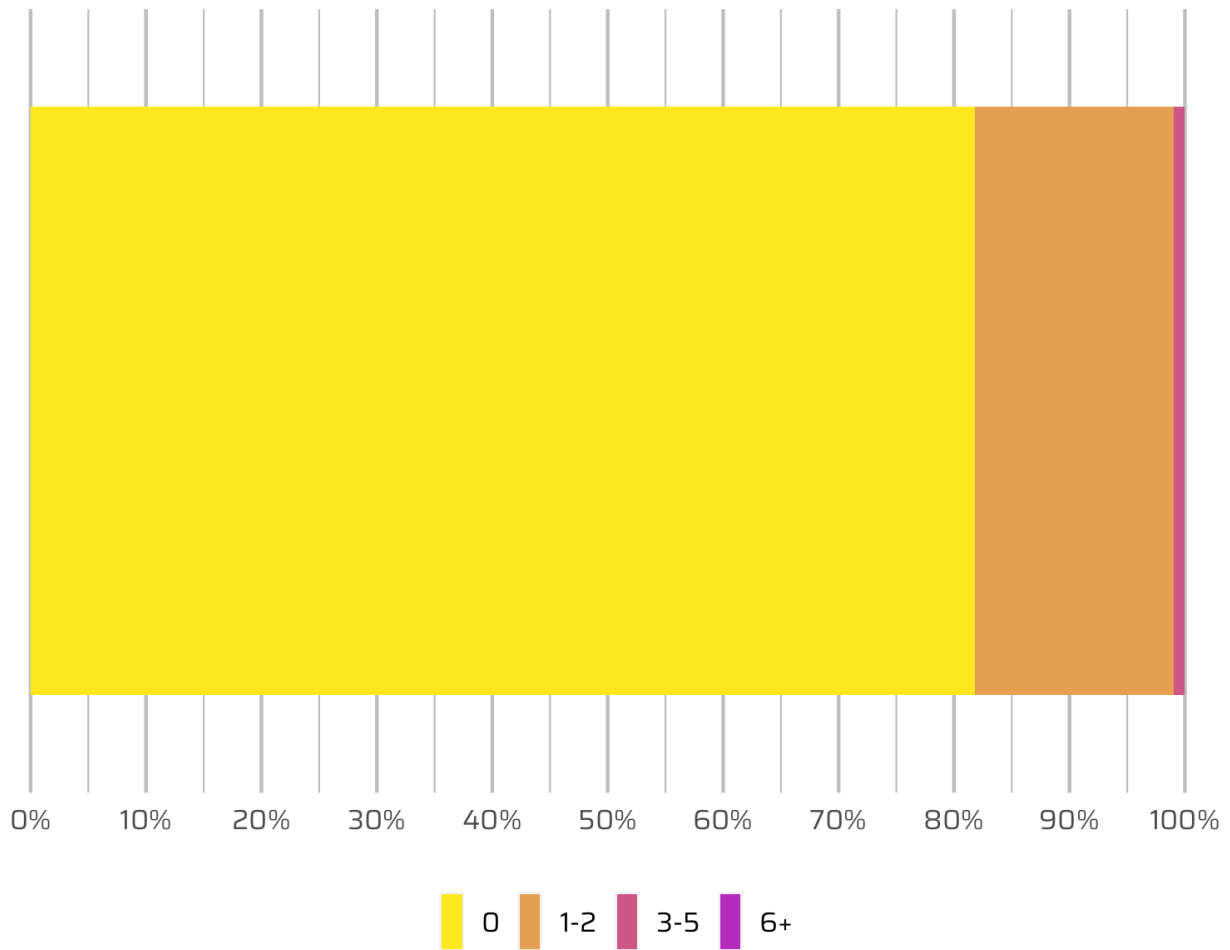


Figure 13: Frequency respondents have sought NHS A&E or Emergency support.

Table 13: Frequency respondents have sought NHS A&E or Emergency support.

Frequency	Respondents	Percentage
6+	0	0
3-5	2	1
1-2	35	17
0	166	82

Gender: Frequency NHS A&E/Emergency Support Sought

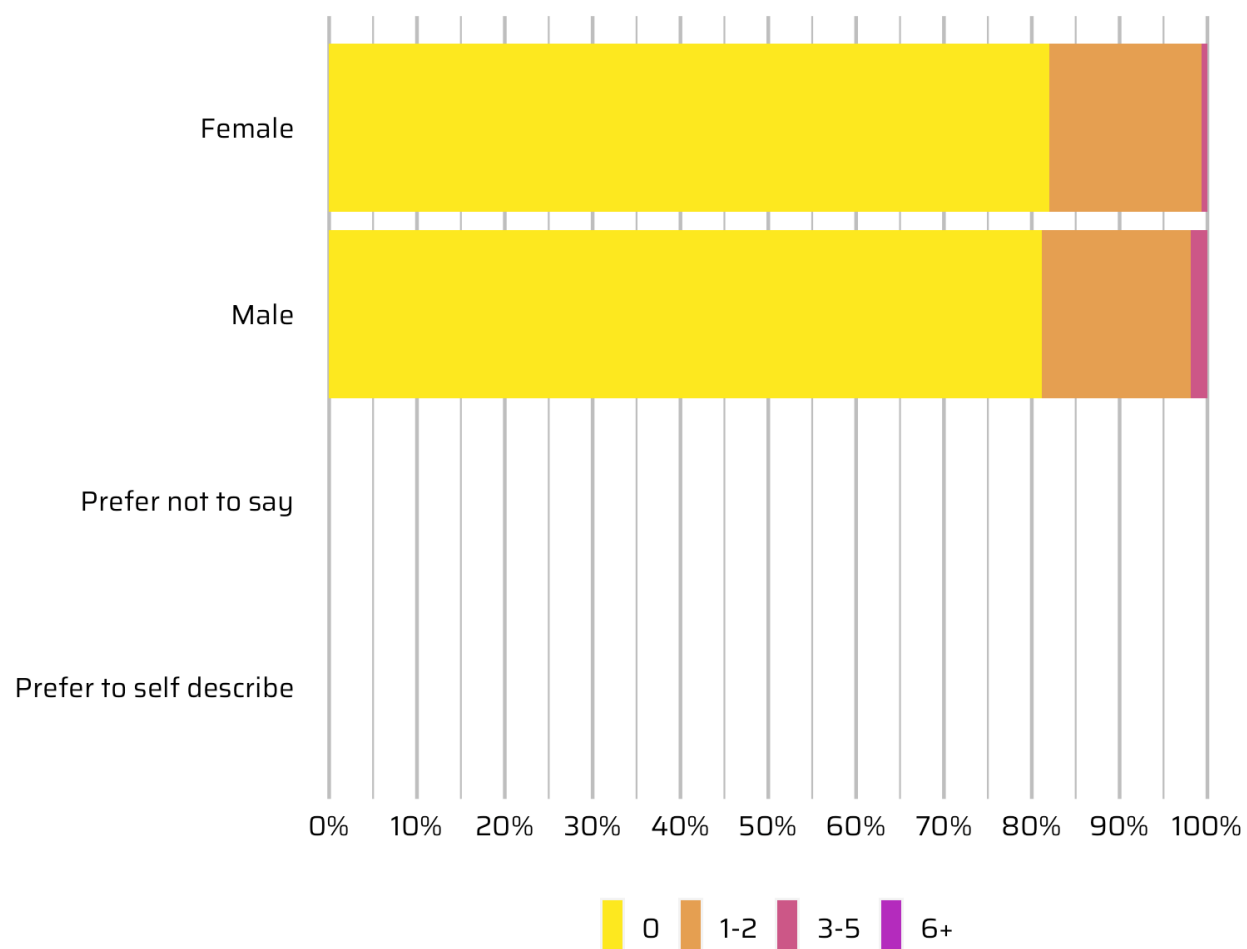


Figure 14: Frequency respondents have sought NHS A&E or Emergency support by gender.

Table 14: Frequency respondents have sought NHS A&E or Emergency support by gender.

Gender	Frequency	Respondents	Percentage
Female	6+	0	0
Female	3-5	1	1
Female	1-2	26	17
Female	0	123	82
Male	6+	0	0
Male	3-5	1	2

Gender	Frequency	Respondents	Percentage
Male	1-2	9	17
Male	0	43	81
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	NaN
Prefer to self-describe	3-5	0	NaN
Prefer to self-describe	1-2	0	NaN
Prefer to self-describe	0	0	NaN

Employment Status: Frequency NHS A&E/Emergency Support Sought

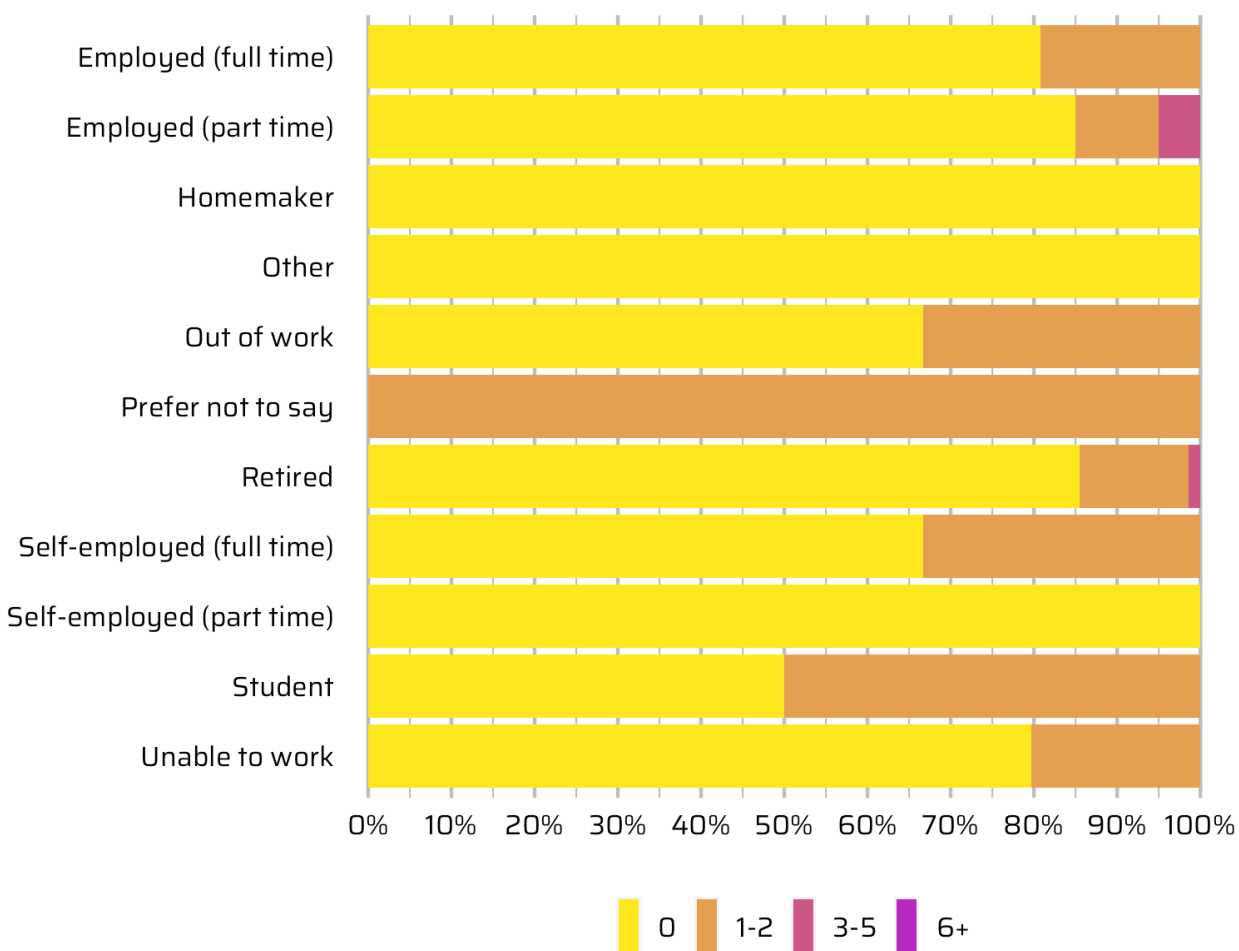


Figure 15: Frequency respondents have sought NHS A&E or Emergency support by employment status.

Table 15: Frequency respondents have sought NHS A&E or Emergency support 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	5	19
Employed (full time)	0	21	81
Employed (part time)	6+	0	0
Employed (part time)	3-5	1	5
Employed (part time)	1-2	2	10
Employed (part time)	0	17	85
Homemaker	6+	0	0
Homemaker	3-5	0	0
Homemaker	1-2	0	0
Homemaker	0	1	100
Other	6+	0	0
Other	3-5	0	0
Other	1-2	0	0
Other	0	3	100
Out of work	6+	0	0
Out of work	3-5	0	0
Out of work	1-2	1	33
Out of work	0	2	67
Prefer not to say	6+	0	0
Prefer not to say	3-5	0	0
Prefer not to say	1-2	1	100
Prefer not to say	0	0	0
Retired	6+	0	0
Retired	3-5	1	1
Retired	1-2	9	13
Retired	0	59	86

Employment Status	Frequency	Respondents	Percentage
Self-employed (full time)	6+	0	0
Self-employed (full time)	3-5	0	0
Self-employed (full time)	1-2	2	33
Self-employed (full time)	0	4	67
Self-employed (part time)	6+	0	0
Self-employed (part time)	3-5	0	0
Self-employed (part time)	1-2	0	0
Self-employed (part time)	0	3	100
Student	6+	0	0
Student	3-5	0	0
Student	1-2	1	50
Student	0	1	50
Unable to work	6+	0	0
Unable to work	3-5	0	0
Unable to work	1-2	14	20
Unable to work	0	55	80

Number of Dependents: Frequency NHS A&E/Emergency Support Sought

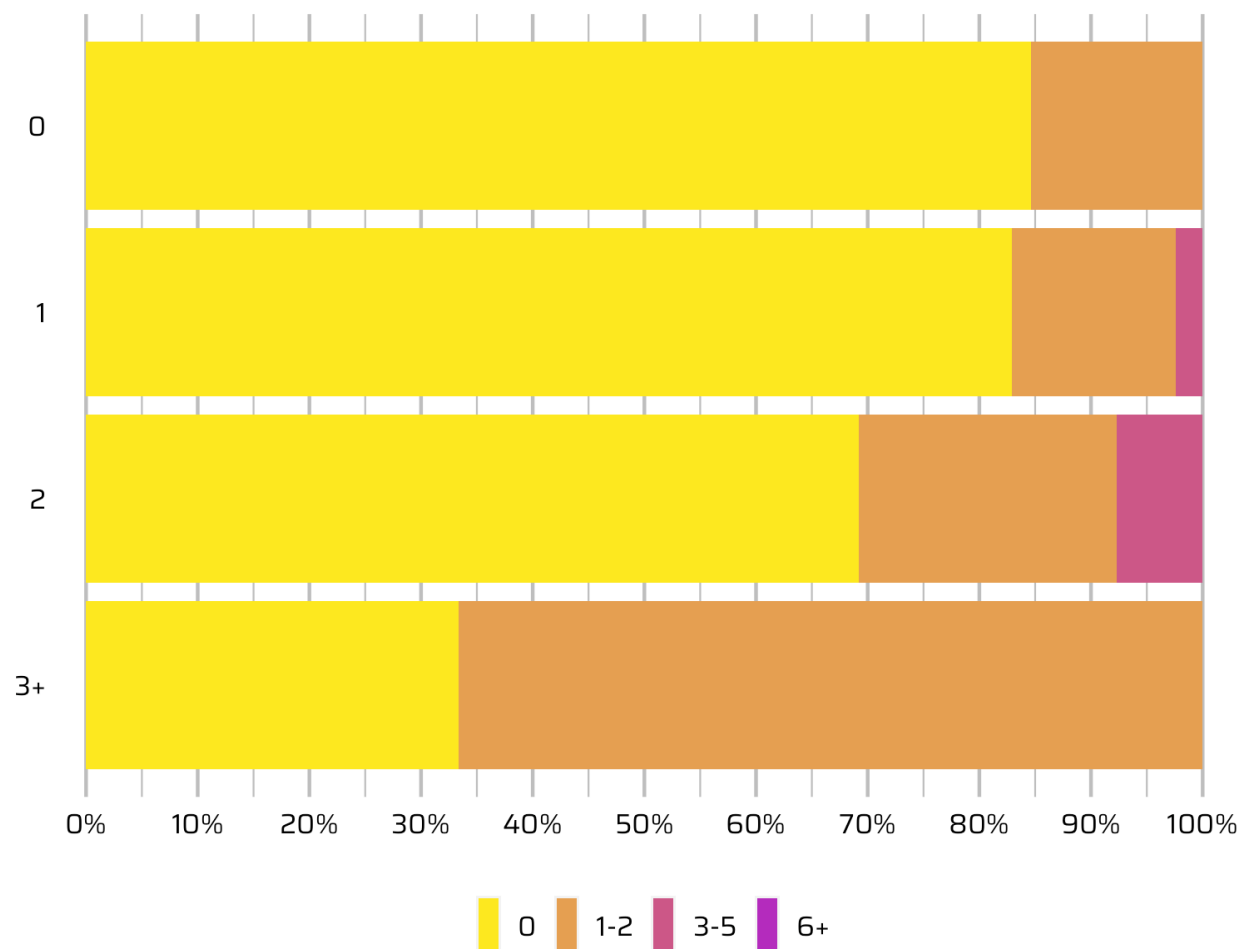


Figure 16: Frequency respondents have sought NHS A&E or Emergency support by number of dependents.

Table 16: Frequency respondents have sought NHS A&E or Emergency support employment status by number of dependents.

Dependents	Frequency	Respondents	Percentage
0	6+	0	0
0	3-5	0	0
0	1-2	22	15
0	0	121	85
1	6+	0	0
1	3-5	1	2

Dependents	Frequency	Respondents	Percentage
1	1-2	6	15
1	0	34	83
2	6+	0	0
2	3-5	1	8
2	1-2	3	23
2	0	9	69
3+	6+	0	0
3+	3-5	0	0
3+	1-2	4	67
3+	0	2	33

Anxious or Hopeless Feeling: Frequency NHS A&E/Emergency Support Sought

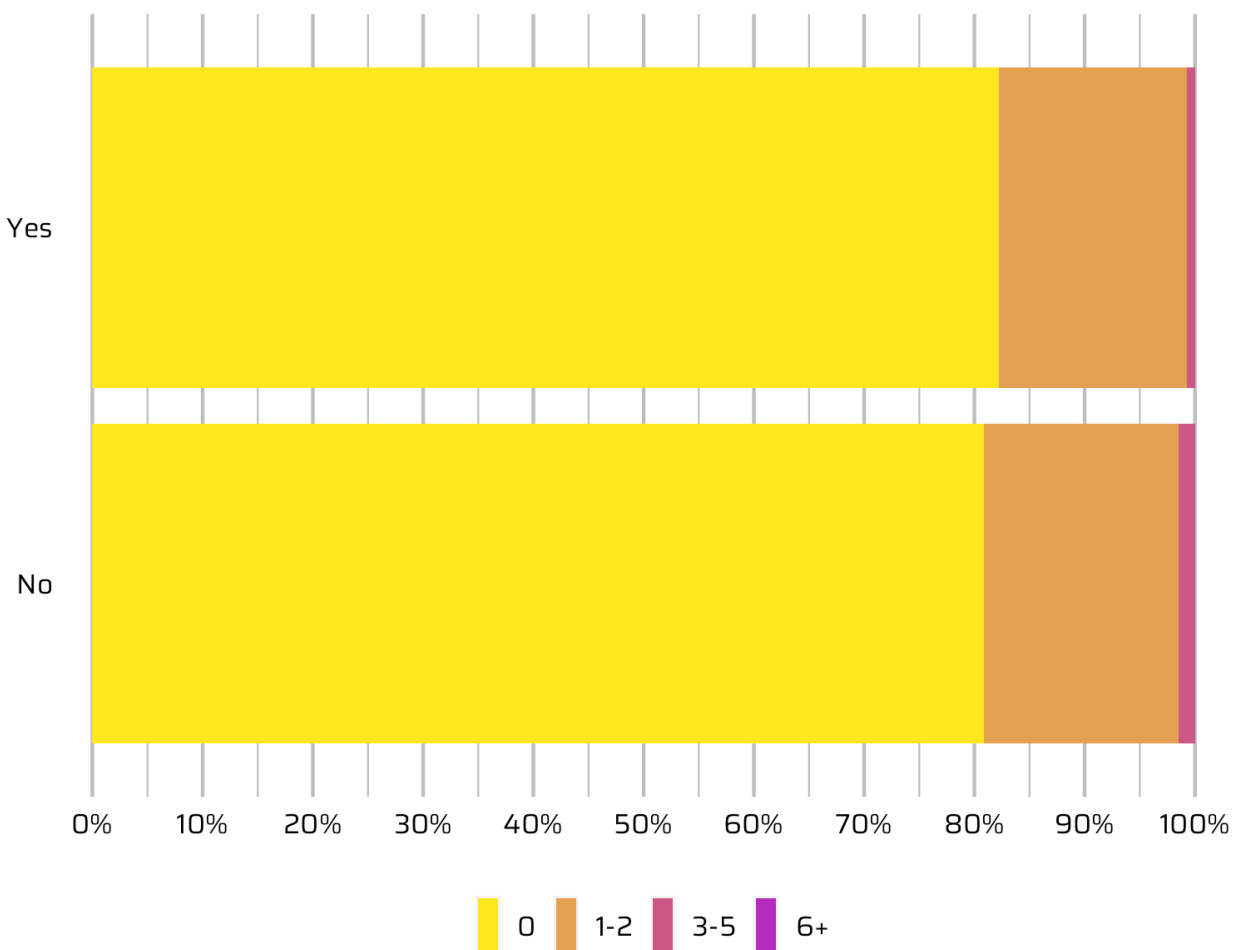


Figure 17: Frequency respondents have sought NHS A&E or Emergency support by feeling anxious or hopeless.

Table 17: Frequency respondents have sought NHS A&E or Emergency support by feeling anxious or hopeless.

Anxious or Hopeless	Frequency	Respondents	Percentage
Yes	6+	0	0
Yes	3-5	1	1
Yes	1-2	23	17
Yes	0	111	82
No	6+	0	0
No	3-5	1	1
No	1-2	12	18
No	0	55	81

Cancellation or Delay of Care: Frequency NHS A&E/Emergency Support Sought

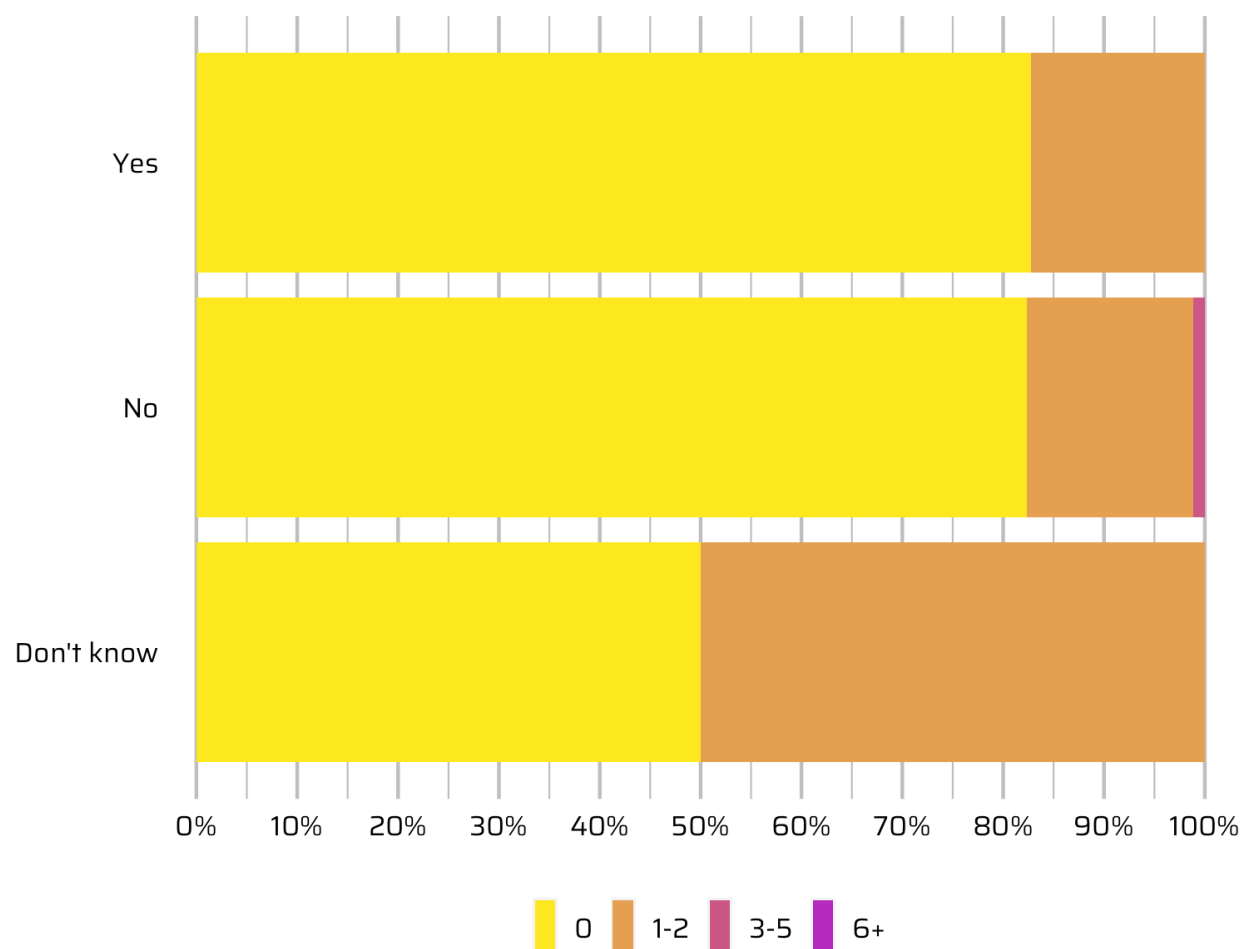


Figure 18: Frequency respondents have sought NHS A&E or Emergency support by cancellations or delays in care.

Table 18: Frequency respondents have sought NHS A&E or Emergency support by cancellations or delays in care.

Cancellation	Frequency	Respondents	Percentage
Yes	6+	0	0
Yes	3-5	0	0
Yes	1-2	5	17
Yes	0	24	83
No	6+	0	0
No	3-5	2	1

Cancellation	Frequency	Respondents	Percentage
No	1-2	28	16
No	0	140	82
Don't know	6+	0	0
Don't know	3-5	0	0
Don't know	1-2	2	50
Don't know	0	2	50

Financial Status: Frequency NHS A&E/Emergency Support Sought

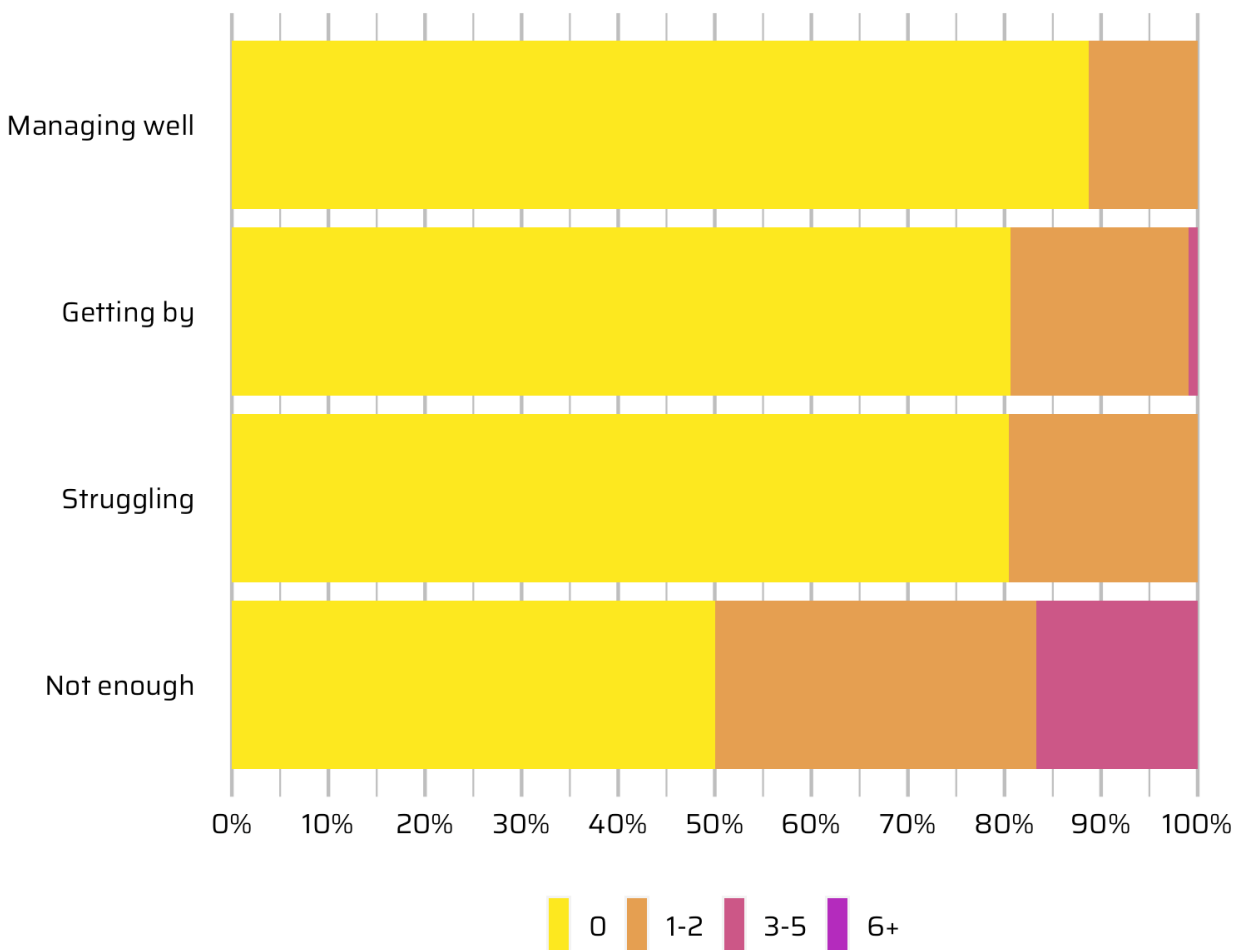


Figure 19: Frequency respondents have sought NHS A&E or Emergency support by financial status.

Table 19: Frequency respondents have sought NHS A&E or Emergency support by financial status.

Financial Status	Frequency	Respondents	Percentage
Managing well	6+	0	0
Managing well	3-5	0	0
Managing well	1-2	6	11
Managing well	0	47	89
Getting by	6+	0	0
Getting by	3-5	1	1
Getting by	1-2	19	18
Getting by	0	83	81
Struggling	6+	0	0
Struggling	3-5	0	0
Struggling	1-2	8	20
Struggling	0	33	80
Not enough	6+	0	0
Not enough	3-5	1	17
Not enough	1-2	2	33
Not enough	0	3	50

Age: Frequency NHS A&E/Emergency Support Sought

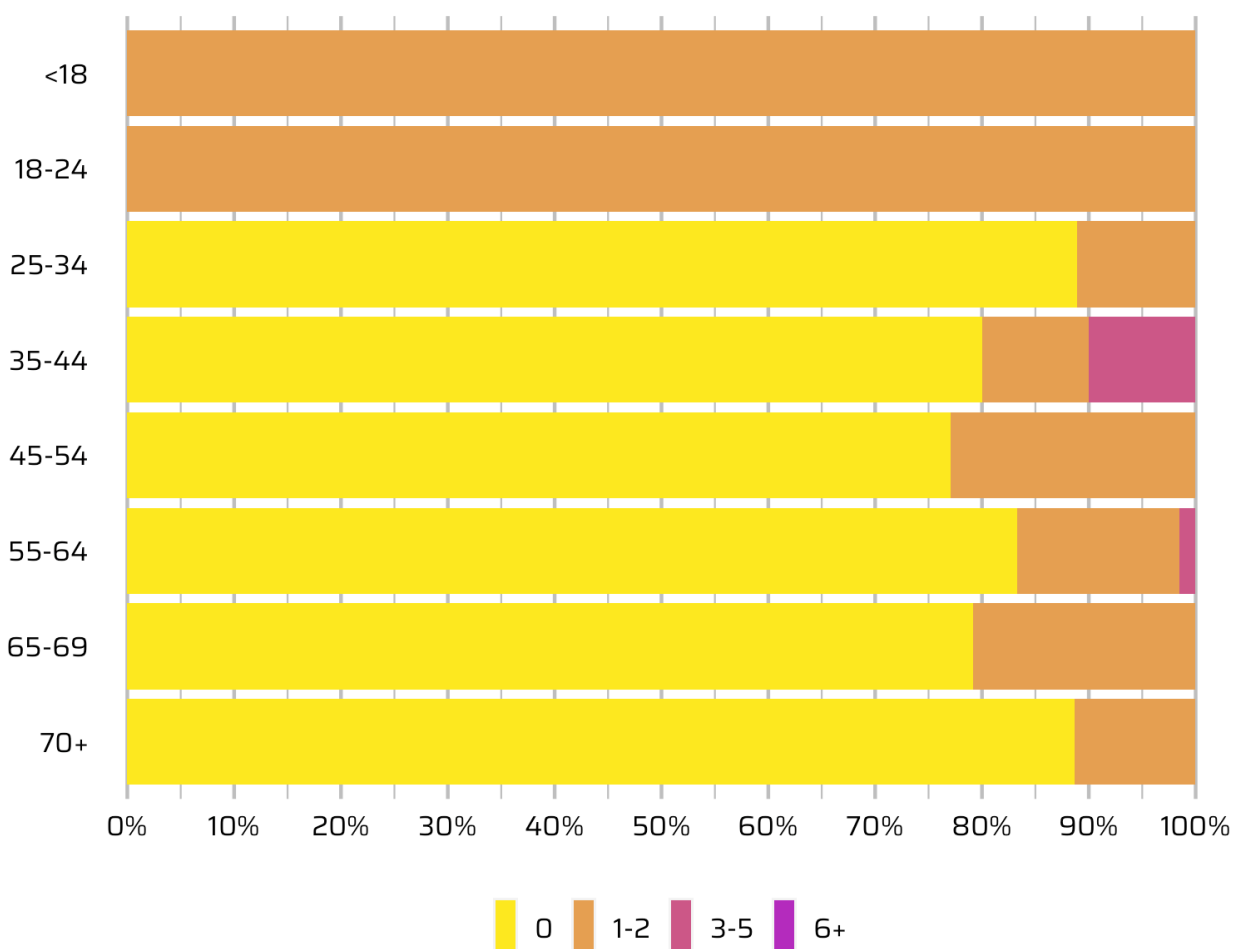


Figure 20: Frequency respondents have sought NHS A&E or Emergency support by age.

Table 20: Frequency respondents have sought NHS A&E or Emergency support by age.

Age	Frequency	Respondents	Percentage
<18	6+	0	0
<18	3-5	0	0
<18	1-2	1	100
<18	0	0	0
18-24	6+	0	0
18-24	3-5	0	0

Age	Frequency	Respondents	Percentage
18-24	1-2	1	100
18-24	0	0	0
25-34	6+	0	0
25-34	3-5	0	0
25-34	1-2	1	11
25-34	0	8	89
35-44	6+	0	0
35-44	3-5	1	10
35-44	1-2	1	10
35-44	0	8	80
45-54	6+	0	0
45-54	3-5	0	0
45-54	1-2	11	23
45-54	0	37	77
55-64	6+	0	0
55-64	3-5	1	2
55-64	1-2	10	15
55-64	0	55	83
65-69	6+	0	0
65-69	3-5	0	0
65-69	1-2	5	21
65-69	0	19	79
70+	6+	0	0
70+	3-5	0	0
70+	1-2	5	11
70+	0	39	89

Treatment, Care, or Support Accessed

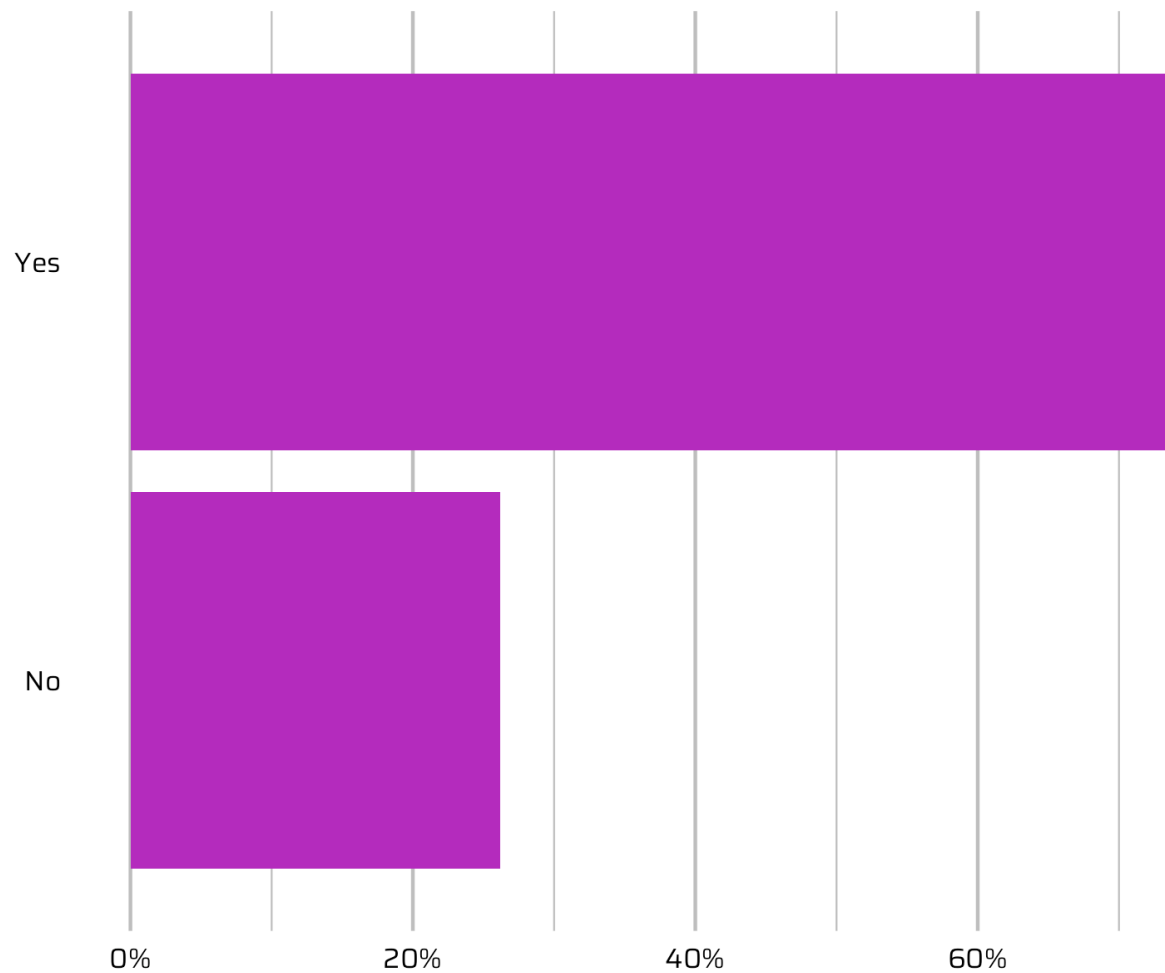


Figure 21: Numbers of respondents reporting they have accessed treatment, care and support services.

Table 21: Numbers of respondents reporting they have accessed treatment, care and support services

Access	Respondents	Percentage
Yes	203	74
No	72	26

Overall Experience of Treatment, Care and Support

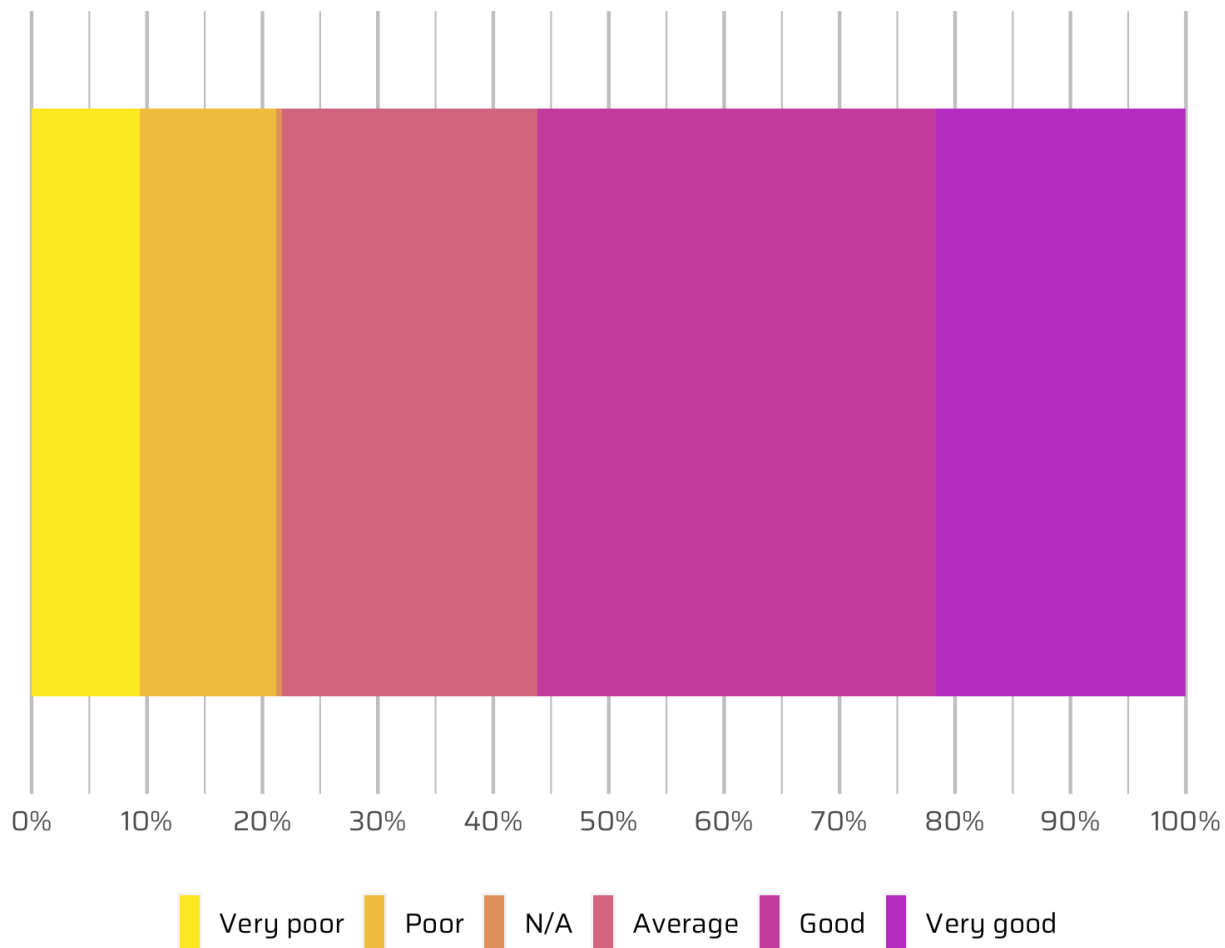


Figure 22: Experience of those respondents reporting they have accessed treatment, care and support services.

Table 22: Experience of those respondents reporting they have accessed treatment, care and support services.

Experience	Respondents	Percentage
Very good	44	22
Good	70	34
Average	45	22
N/A	1	0
Poor	24	12
Very poor	19	9

Gender: Overall experience of Treatment, Care and Support

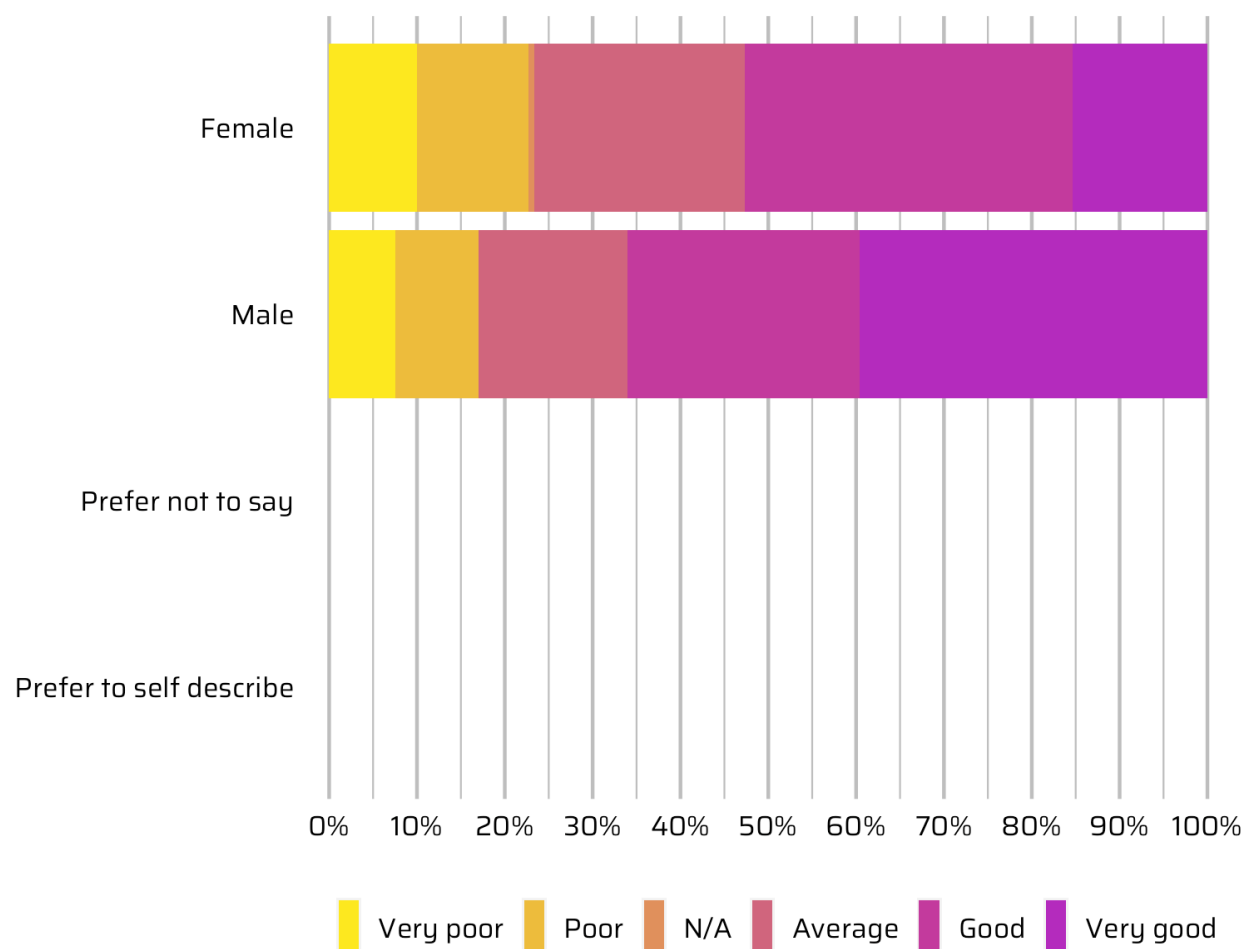


Figure 23: Experience of those respondents reporting they have accessed treatment, care and support services by gender.

Table 23: Experience of those respondents reporting they have accessed treatment, care and support services by gender.

Gender	Experience	Respondents	Percentage
Female	Very good	23	15
Female	Good	56	37
Female	Average	36	24
Female	N/A	1	1
Female	Poor	19	13
Female	Very poor	15	10

Gender	Experience	Respondents	Percentage
Male	Very good	21	40
Male	Good	14	26
Male	Average	9	17
Male	N/A	0	0
Male	Poor	5	9
Male	Very poor	4	8
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

Employment Status: Overall experience of Treatment, Care and Support

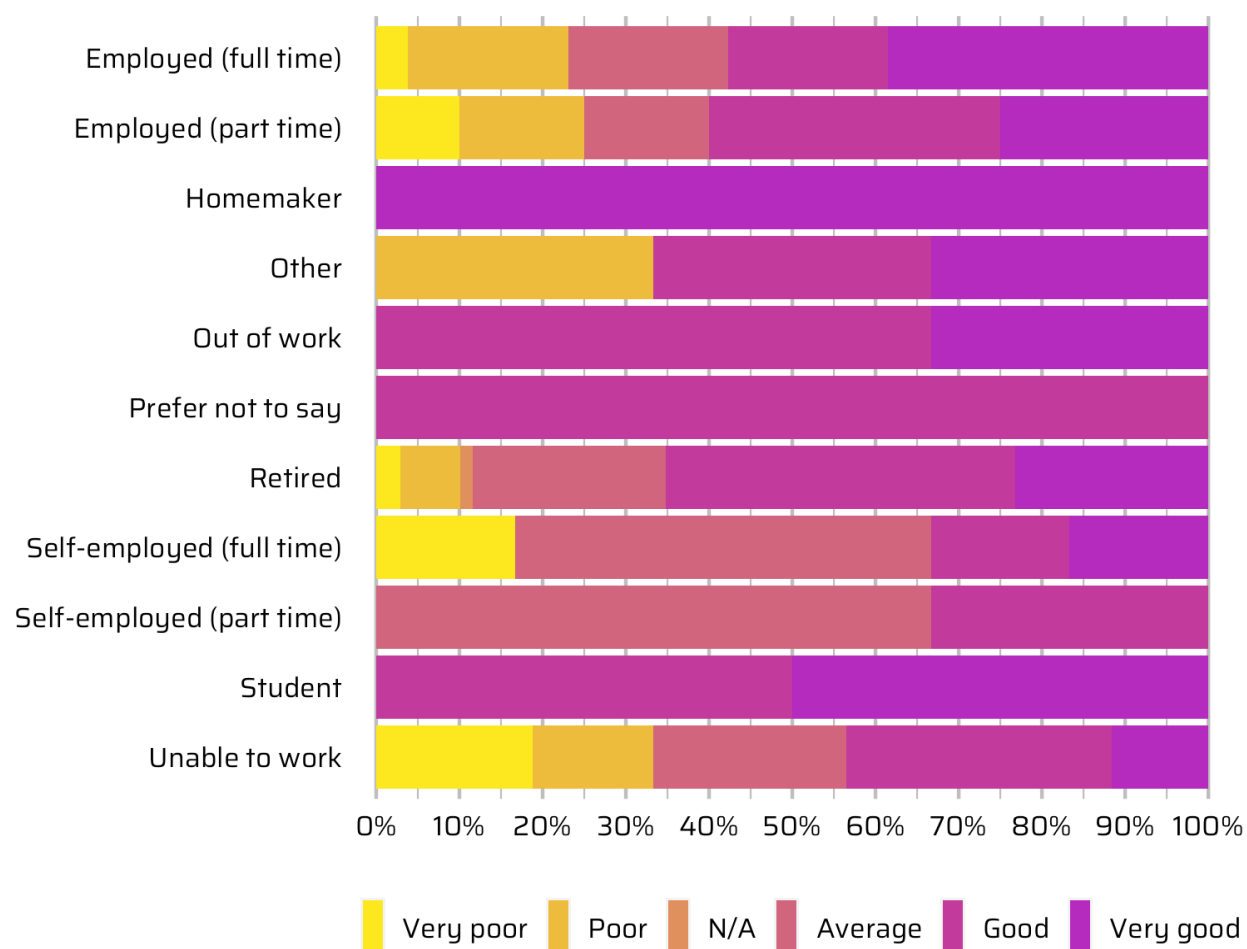


Figure 24: Experience of those respondents reporting they have accessed treatment, care and support services by employment status.

Table 24: Experience of those respondents reporting they have accessed treatment, care and support services by employment status.

Employment Status	Experience	Respondents	Percentage
Employed (full time)	Very good	10	38
Employed (full time)	Good	5	19
Employed (full time)	Average	5	19
Employed (full time)	N/A	0	0
Employed (full time)	Poor	5	19
Employed (full time)	Very poor	1	4

Employment Status	Experience	Respondents	Percentage
Employed (part time)	Very good	5	25
Employed (part time)	Good	7	35
Employed (part time)	Average	3	15
Employed (part time)	N/A	0	0
Employed (part time)	Poor	3	15
Employed (part time)	Very poor	2	10
Homemaker	Very good	1	100
Homemaker	Good	0	0
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	1	33
Other	Very poor	0	0
Out of work	Very good	1	33
Out of work	Good	2	67
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	16	23
Retired	Good	29	42
Retired	Average	16	23

Employment Status	Experience	Respondents	Percentage
Retired	N/A	1	1
Retired	Poor	5	7
Retired	Very poor	2	3
Self-employed (full time)	Very good	1	17
Self-employed (full time)	Good	1	17
Self-employed (full time)	Average	3	50
Self-employed (full time)	N/A	0	0
Self-employed (full time)	Poor	0	0
Self-employed (full time)	Very poor	1	17
Self-employed (part time)	Very good	0	0
Self-employed (part time)	Good	1	33
Self-employed (part time)	Average	2	67
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	1	50
Student	Good	1	50
Student	Average	0	0
Student	N/A	0	0
Student	Poor	0	0
Student	Very poor	0	0
Unable to work	Very good	8	12
Unable to work	Good	22	32
Unable to work	Average	16	23
Unable to work	N/A	0	0
Unable to work	Poor	10	14
Unable to work	Very poor	13	19

Number of Dependents: Overall experience of Treatment, Care and Support

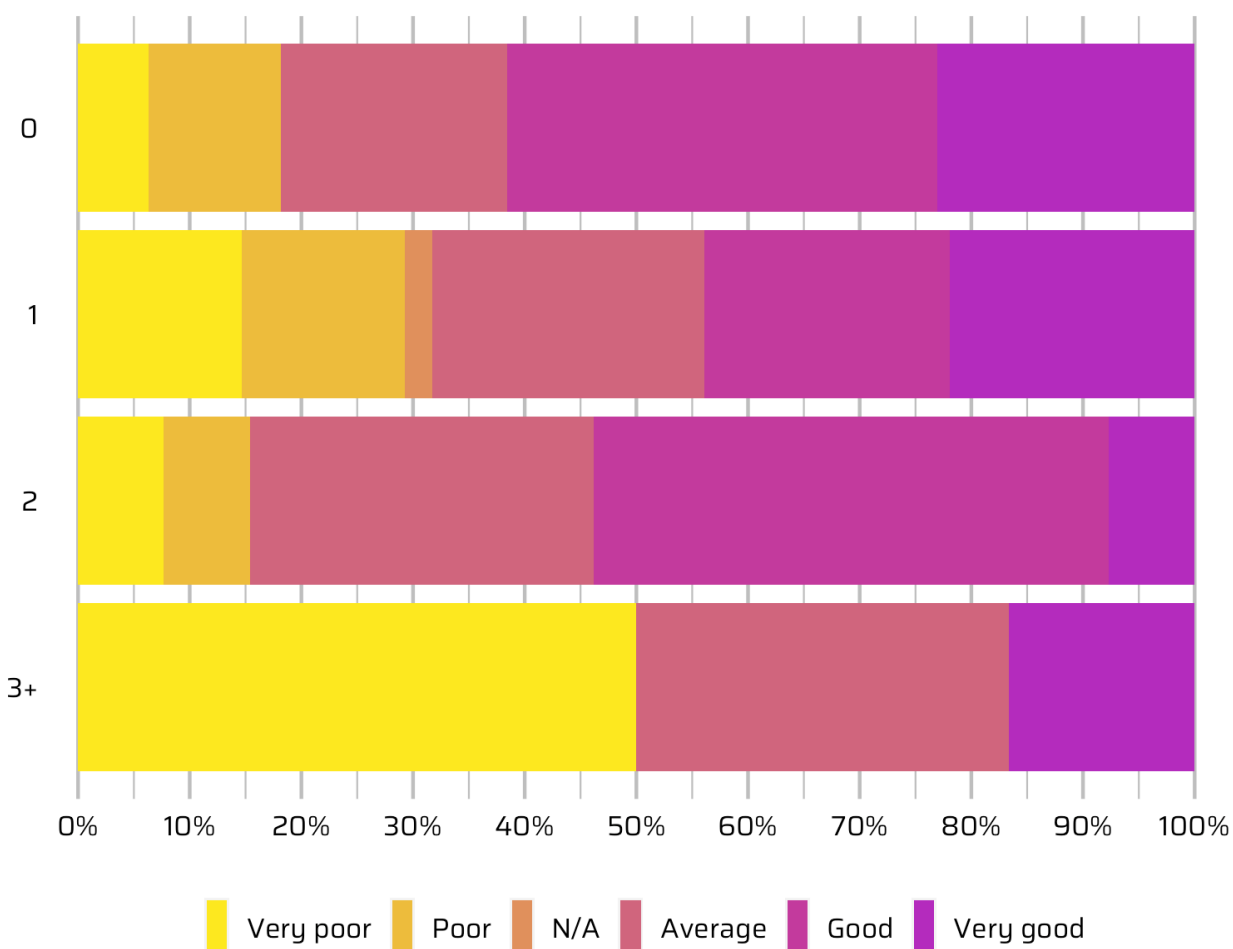


Figure 25: Experience of those respondents reporting they have accessed treatment, care and support services by number of dependents

Table 25: Experience of those respondents reporting they have accessed treatment, care and support services by number of dependents

Dependents	Experience	Respondents	Percentage
0	Very good	33	23
0	Good	55	38
0	Average	29	20
0	N/A	0	0
0	Poor	17	12
0	Very poor	9	6

Dependents	Experience	Respondents	Percentage
1	Very good	9	22
1	Good	9	22
1	Average	10	24
1	N/A	1	2
1	Poor	6	15
1	Very poor	6	15
2	Very good	1	8
2	Good	6	46
2	Average	4	31
2	N/A	0	0
2	Poor	1	8
2	Very poor	1	8
3+	Very good	1	17
3+	Good	0	0
3+	Average	2	33
3+	N/A	0	0
3+	Poor	0	0
3+	Very poor	3	50

Anxious or Hopeless Feeling: Overall experience of Treatment, Care and Support

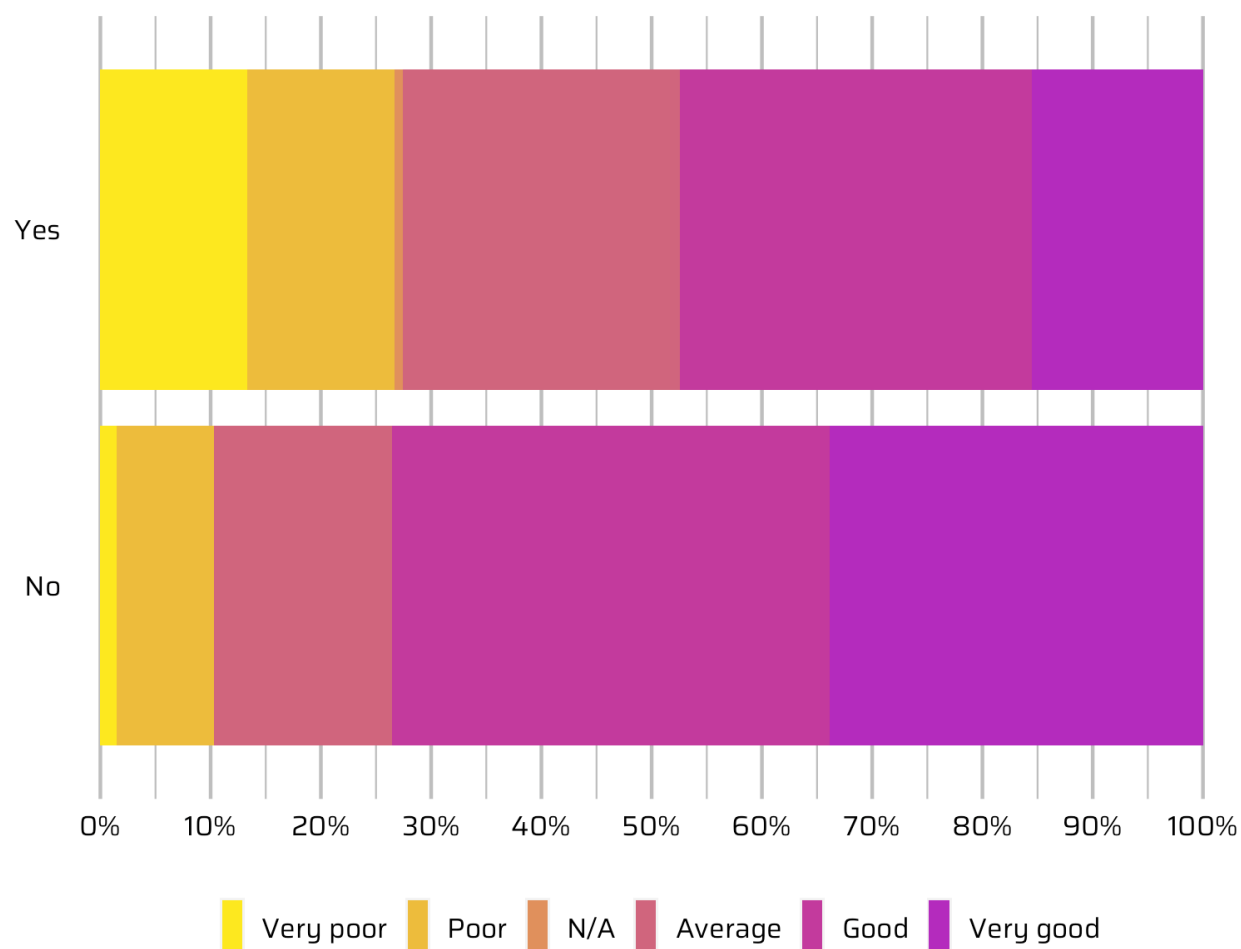


Figure 26: Experience of those respondents reporting they have accessed treatment, care and support services by feeling anxious or hopeless.

Table 26: Experience of those respondents reporting they have accessed treatment, care and support services by feeling anxious or hopeless.

Anxious or Hopeless	Experience	Respondents	Percentage
Yes	Very good	21	16
Yes	Good	43	32
Yes	Average	34	25
Yes	N/A	1	1
Yes	Poor	18	13

Anxious or Hopeless	Experience	Respondents	Percentage
Yes	Very poor	18	13
No	Very good	23	34
No	Good	27	40
No	Average	11	16
No	N/A	0	0
No	Poor	6	9
No	Very poor	1	1

Cancellation or Delay of Care: Overall experience of Treatment, Care and Support

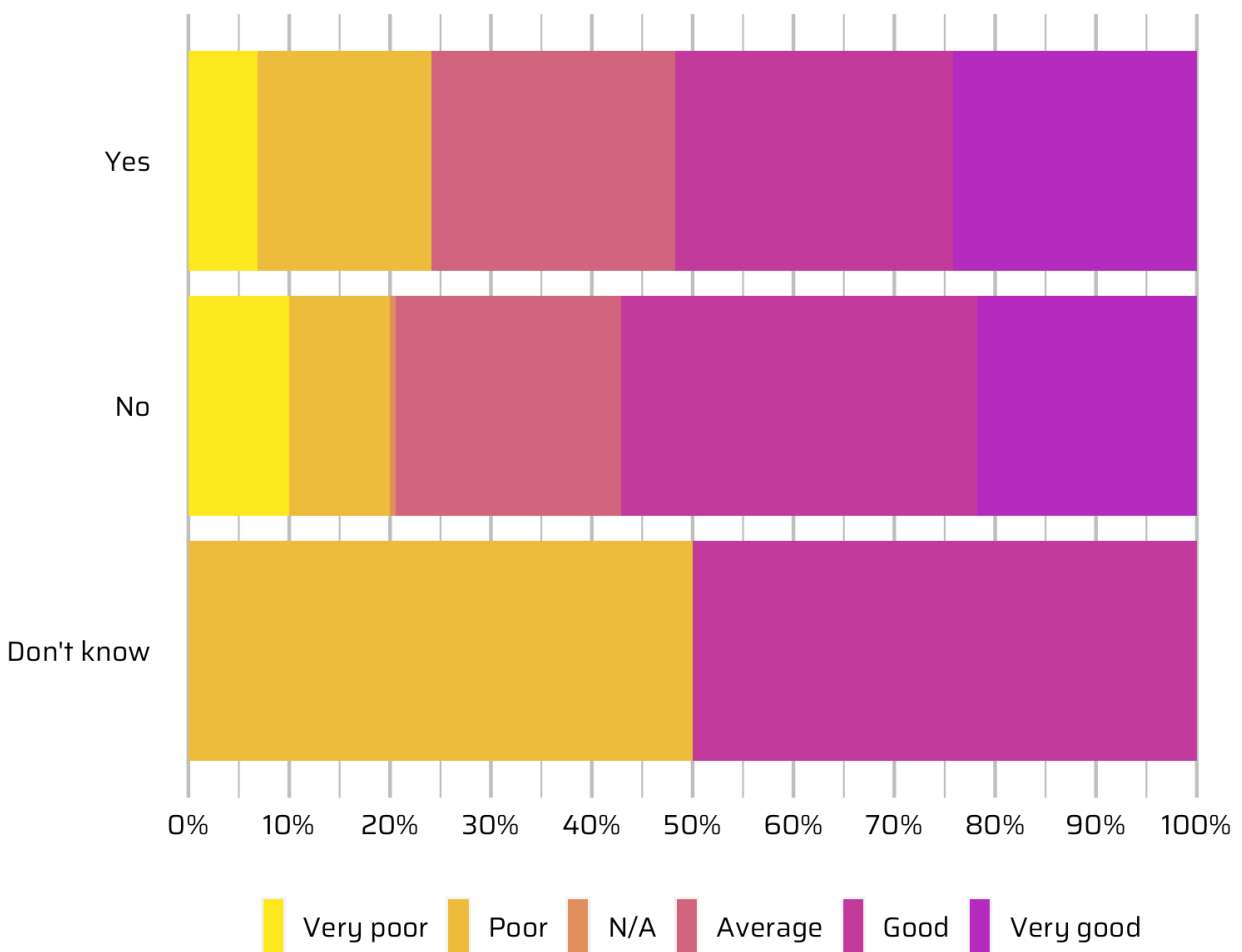


Figure 27: Experience of those respondents reporting they have accessed treatment, care and support services by cancellation or delays in care.

Table 27: Experience of those respondents reporting they have accessed treatment, care and support services by cancellation or delays in care.

Cancellation	Experience	Respondents	Percentage
Yes	Very good	7	24
Yes	Good	8	28
Yes	Average	7	24
Yes	N/A	0	0
Yes	Poor	5	17
Yes	Very poor	2	7
No	Very good	37	22
No	Good	60	35
No	Average	38	22
No	N/A	1	1
No	Poor	17	10
No	Very poor	17	10
Don't know	Very good	0	0
Don't know	Good	2	50
Don't know	Average	0	0
Don't know	N/A	0	0
Don't know	Poor	2	50
Don't know	Very poor	0	0

Financial Status: Overall experience of Treatment, Care and Support

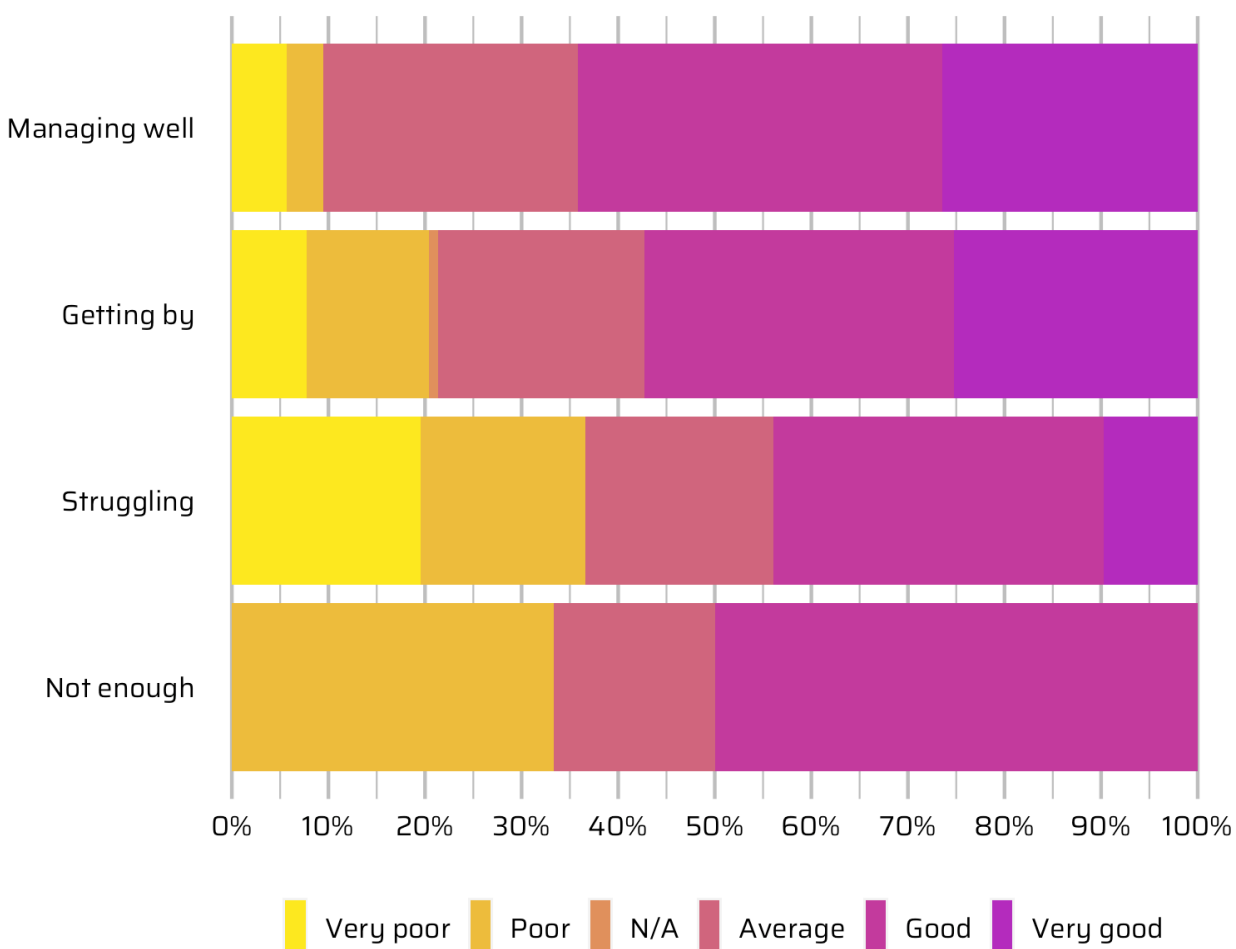


Figure 28: Experience of those respondents reporting they have accessed treatment, care and support services by financial status.

Table 28: Experience of those respondents reporting they have accessed treatment, care and support services by financial status.

Financial Status	Experience	Respondents	Percentage
Managing well	Very good	14	26
Managing well	Good	20	38
Managing well	Average	14	26
Managing well	N/A	0	0
Managing well	Poor	2	4
Managing well	Very poor	3	6

Financial Status	Experience	Respondents	Percentage
Getting by	Very good	26	25
Getting by	Good	33	32
Getting by	Average	22	21
Getting by	N/A	1	1
Getting by	Poor	13	13
Getting by	Very poor	8	8
Struggling	Very good	4	10
Struggling	Good	14	34
Struggling	Average	8	20
Struggling	N/A	0	0
Struggling	Poor	7	17
Struggling	Very poor	8	20
Not enough	Very good	0	0
Not enough	Good	3	50
Not enough	Average	1	17
Not enough	N/A	0	0
Not enough	Poor	2	33
Not enough	Very poor	0	0

Age: Overall experience of Treatment, Care and Support

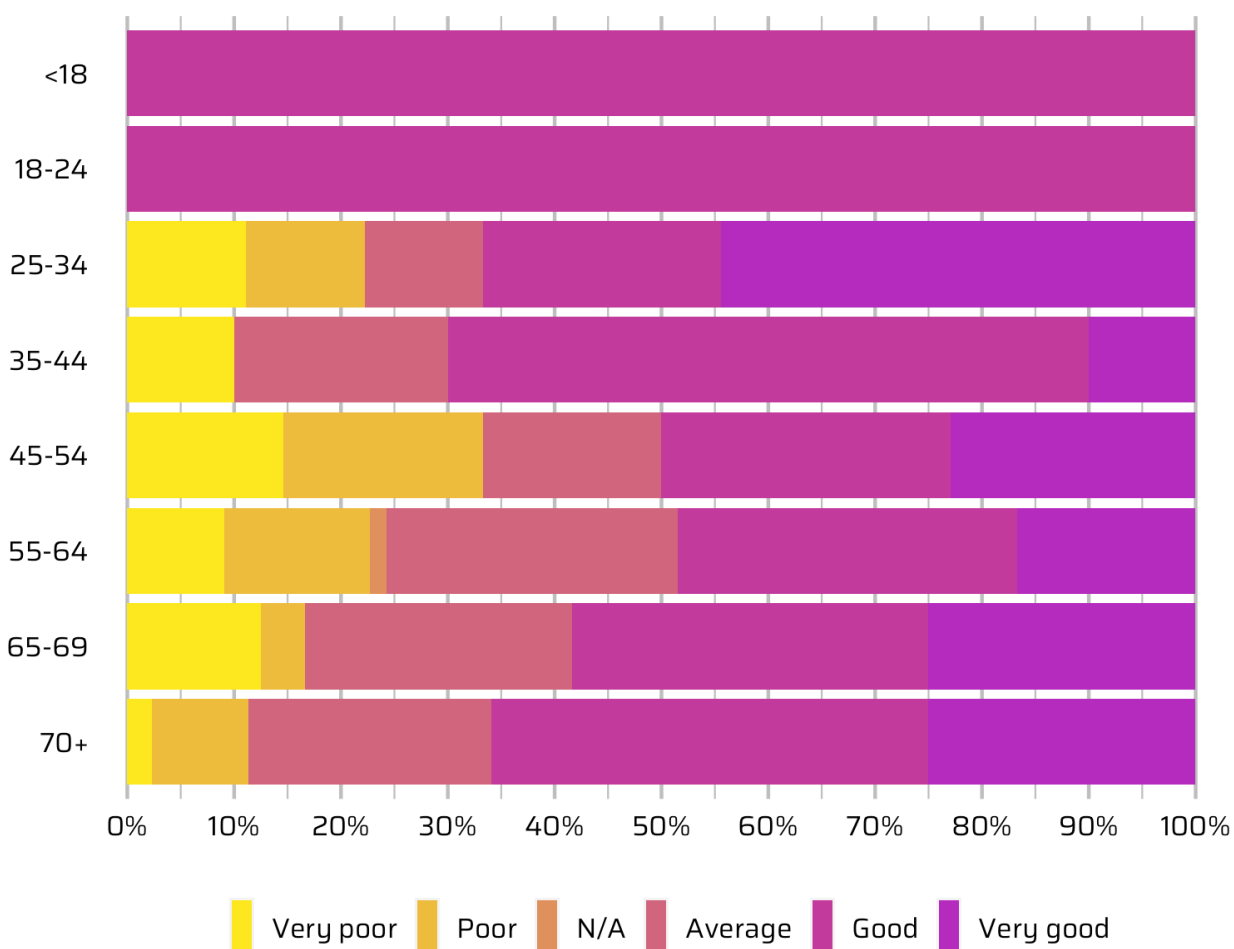


Figure 29 Experience of those respondents reporting they have accessed treatment, care and support services by age.

Table 29 Experience of those respondents reporting they have accessed treatment, care and support services by age.

Age	Experience	Respondents	Percentage
<18	Very good	0	0
<18	Good	1	100
<18	Average	0	0
<18	N/A	0	0
<18	Poor	0	0
<18	Very poor	0	0

Age	Experience	Respondents	Percentage
18-24	Very good	0	0
18-24	Good	1	100
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	4	44
25-34	Good	2	22
25-34	Average	1	11
25-34	N/A	0	0
25-34	Poor	1	11
25-34	Very poor	1	11
35-44	Very good	1	10
35-44	Good	6	60
35-44	Average	2	20
35-44	N/A	0	0
35-44	Poor	0	0
35-44	Very poor	1	10
45-54	Very good	11	23
45-54	Good	13	27
45-54	Average	8	17
45-54	N/A	0	0
45-54	Poor	9	19
45-54	Very poor	7	15
55-64	Very good	11	17
55-64	Good	21	32
55-64	Average	18	27
55-64	N/A	1	2
55-64	Poor	9	14
55-64	Very poor	6	9
65-69	Very good	6	25
65-69	Good	8	33
65-69	Average	6	25

Age	Experience	Respondents	Percentage
65-69	N/A	0	0
65-69	Poor	1	4
65-69	Very poor	3	12
70+	Very good	11	25
70+	Good	18	41
70+	Average	10	23
70+	N/A	0	0
70+	Poor	4	9
70+	Very poor	1	2

Number of Medical Appointments

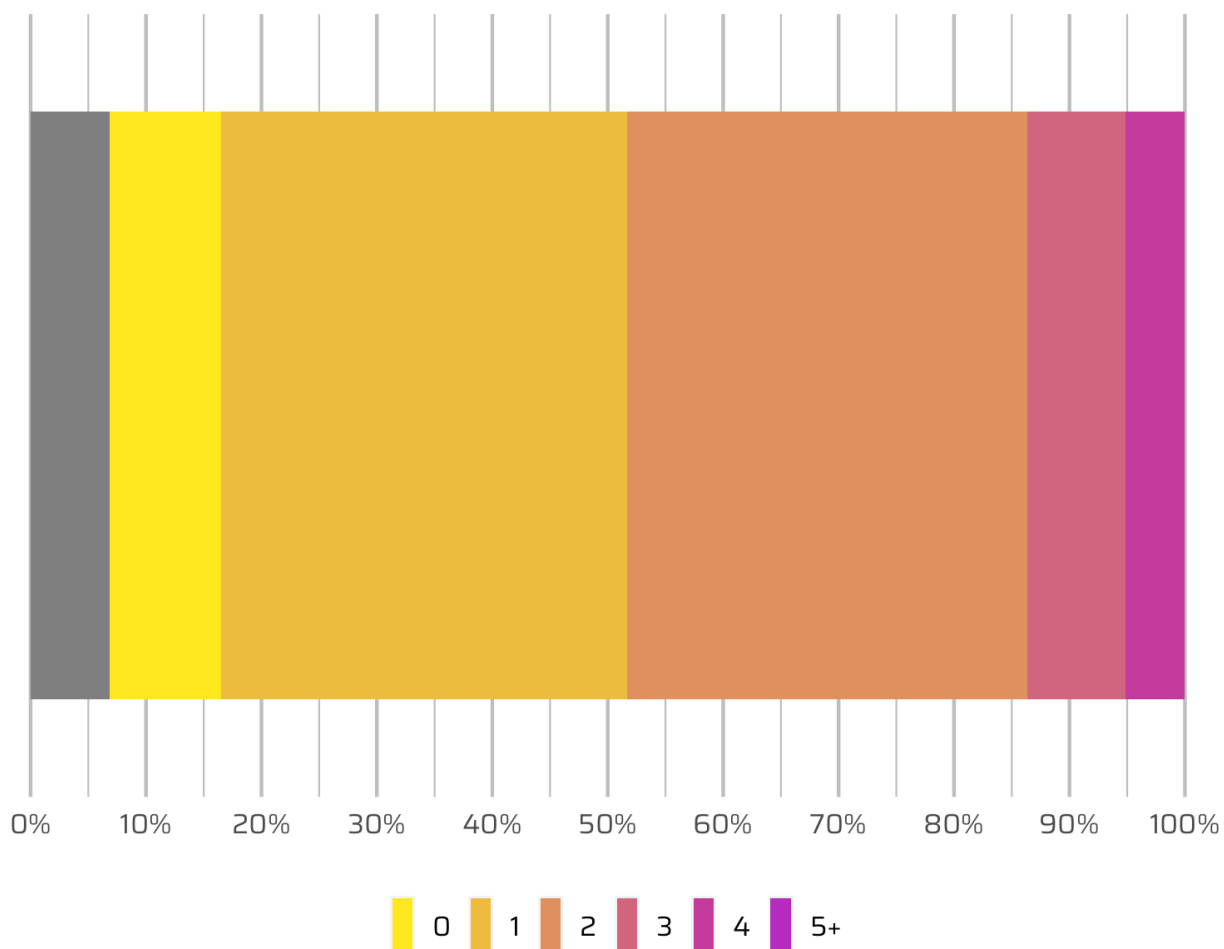


Figure 30: Number of medical appointments attended by respondents.

Table 30: Number of medical appointments attended by respondents.

Number	Respondents	Percentage
5+	0	0
4	9	5
3	15	9
2	61	35
1	62	35
0	17	10
NA	12	7

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.

Helpfulness of Medical Appointments

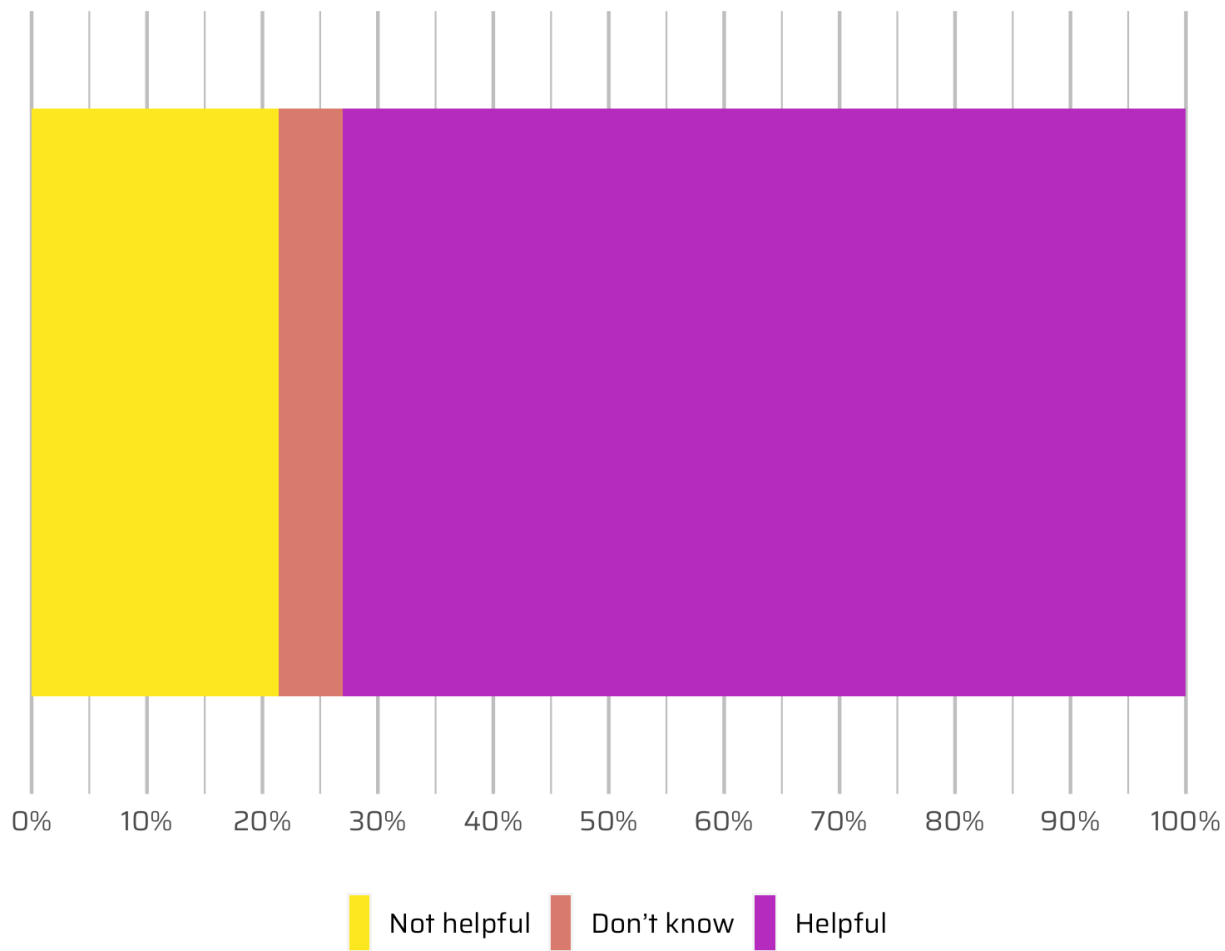


Figure 31: Helpfulness of medical appointments attended by respondents.

Table 31: Helpfulness of medical appointments attended by respondents.

Helpfulness	Observations	Percentage
Helpful	198	73
Don't know	15	6
Not helpful	58	21

Appointment Specialism

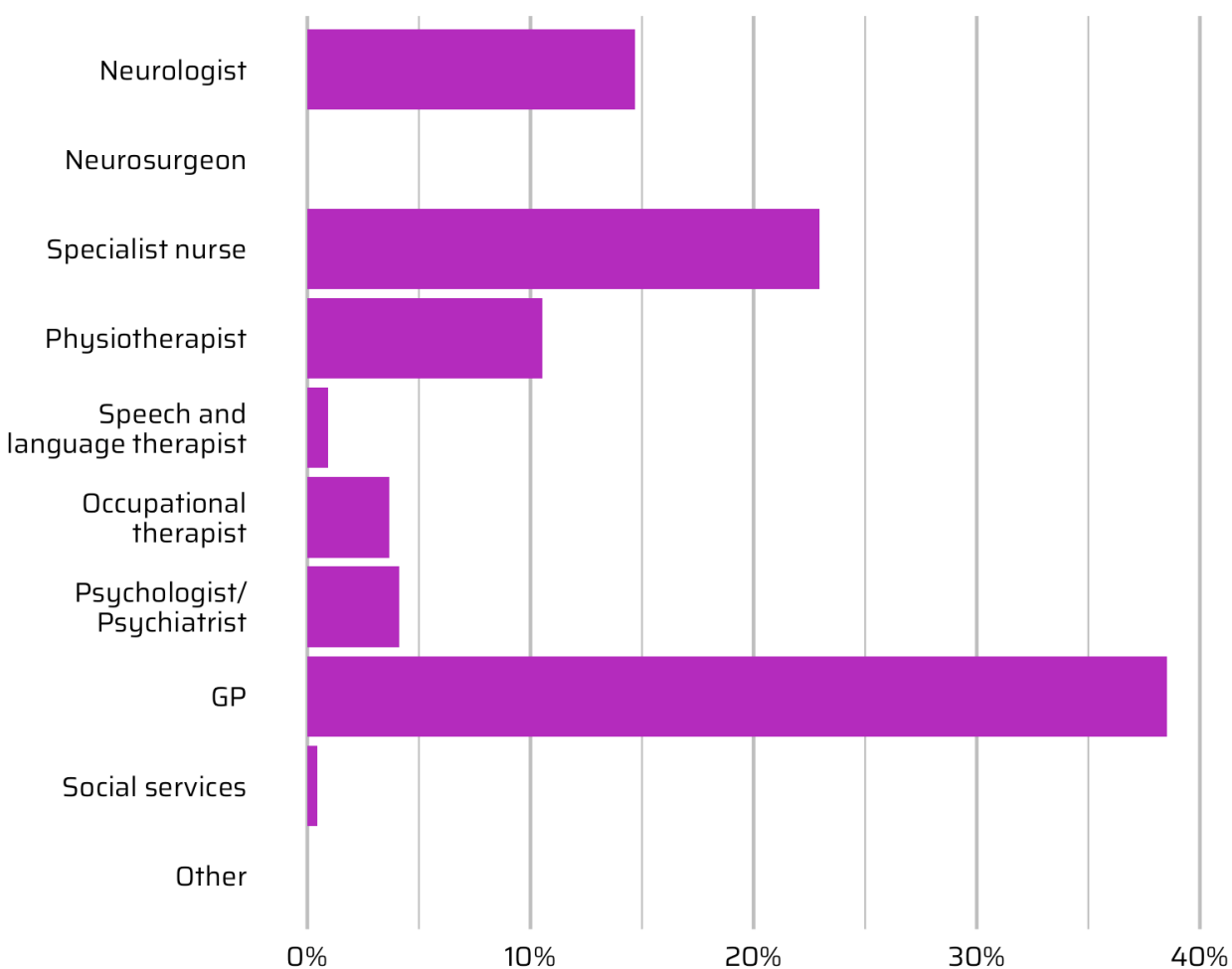


Figure 32: Specialism of the medical appointments attended by respondents.

Table 32: Specialism of the medical appointments attended by respondents.

Specialism	Observations	Percentage
Neurologist	32	15
Neurosurgeon	0	0
Specialist nurse	50	23
Physiotherapist	23	11
Speech and language therapist	2	1
Occupational therapist	8	4
Psychologist/Psychiatrist	9	4
GP	84	39

Specialism	Observations	Percentage
Social services	1	0
Other	0	0
NA	9	4

Specialty: Helpfulness Medical Appointment

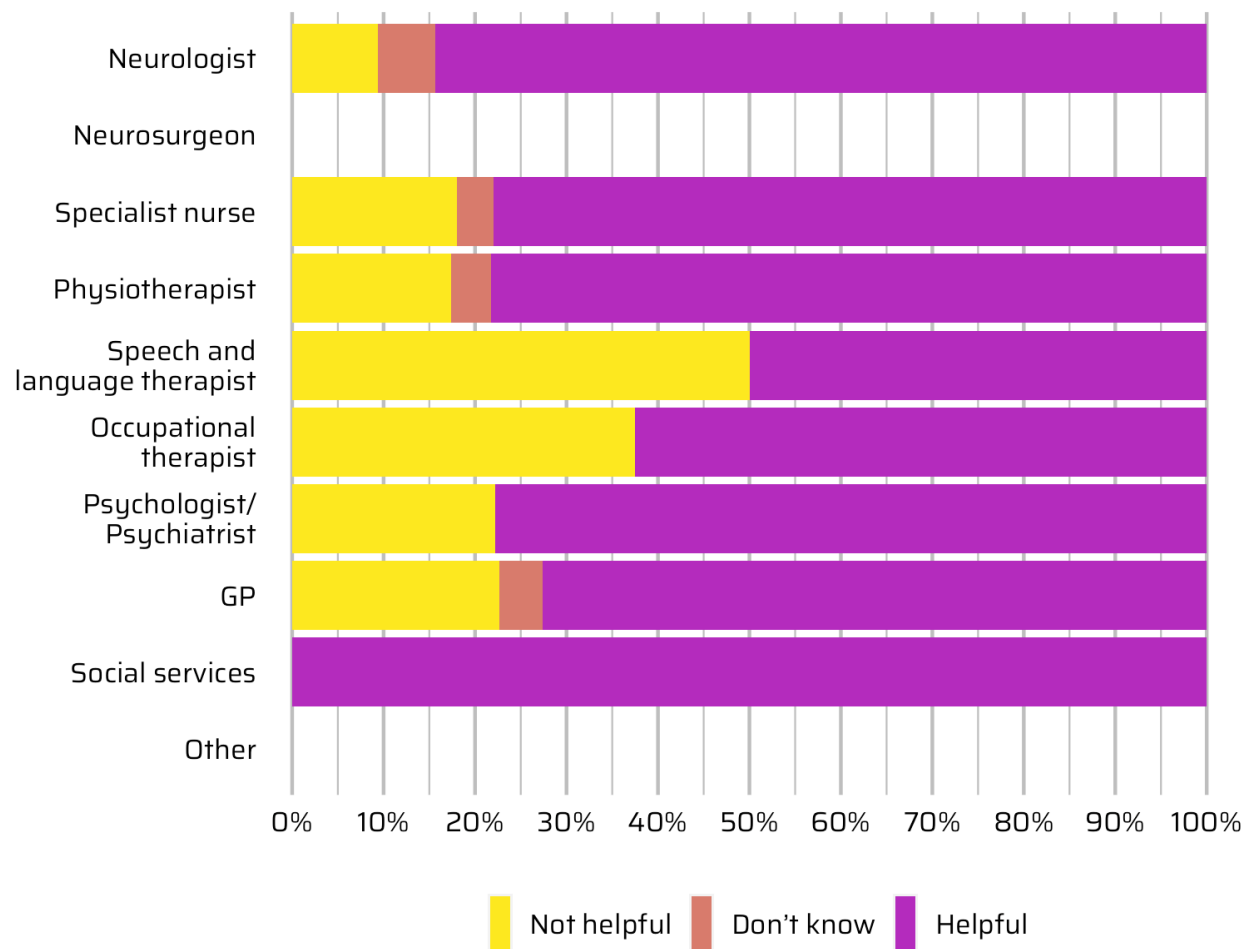


Figure 33: Helpfulness of medical appointment by the specialism.

Table 33: Helpfulness of medical appointment by the specialism.

Specialism	Helpfulness	Observations	Percentage
Neurologist	Helpful	27	84
Neurologist	Don't know	2	6

Specialism	Helpfulness	Observations	Percentage
Neurologist	Not helpful	3	9
Neurosurgeon	Helpful	0	NaN
Neurosurgeon	Don't know	0	NaN
Neurosurgeon	Not helpful	0	NaN
Specialist nurse	Helpful	39	78
Specialist nurse	Don't know	2	4
Specialist nurse	Not helpful	9	18
Physiotherapist	Helpful	18	78
Physiotherapist	Don't know	1	4
Physiotherapist	Not helpful	4	17
Speech and language therapist	Helpful	1	50
Speech and language therapist	Don't know	0	0
Speech and language therapist	Not helpful	1	50
Occupational therapist	Helpful	5	62
Occupational therapist	Don't know	0	0
Occupational therapist	Not helpful	3	38
Psychologist/Psychiatrist	Helpful	7	78
Psychologist/Psychiatrist	Don't know	0	0
Psychologist/Psychiatrist	Not helpful	2	22
GP	Helpful	61	73
GP	Don't know	4	5
GP	Not helpful	19	23
Social services	Helpful	1	100
Social services	Don't know	0	0
Social services	Not helpful	0	0
Other	Helpful	0	NaN
Other	Don't know	0	NaN
Other	Not helpful	0	NaN
NA	Helpful	4	44
NA	Don't know	2	22
NA	Not helpful	3	33

Mode of Appointment

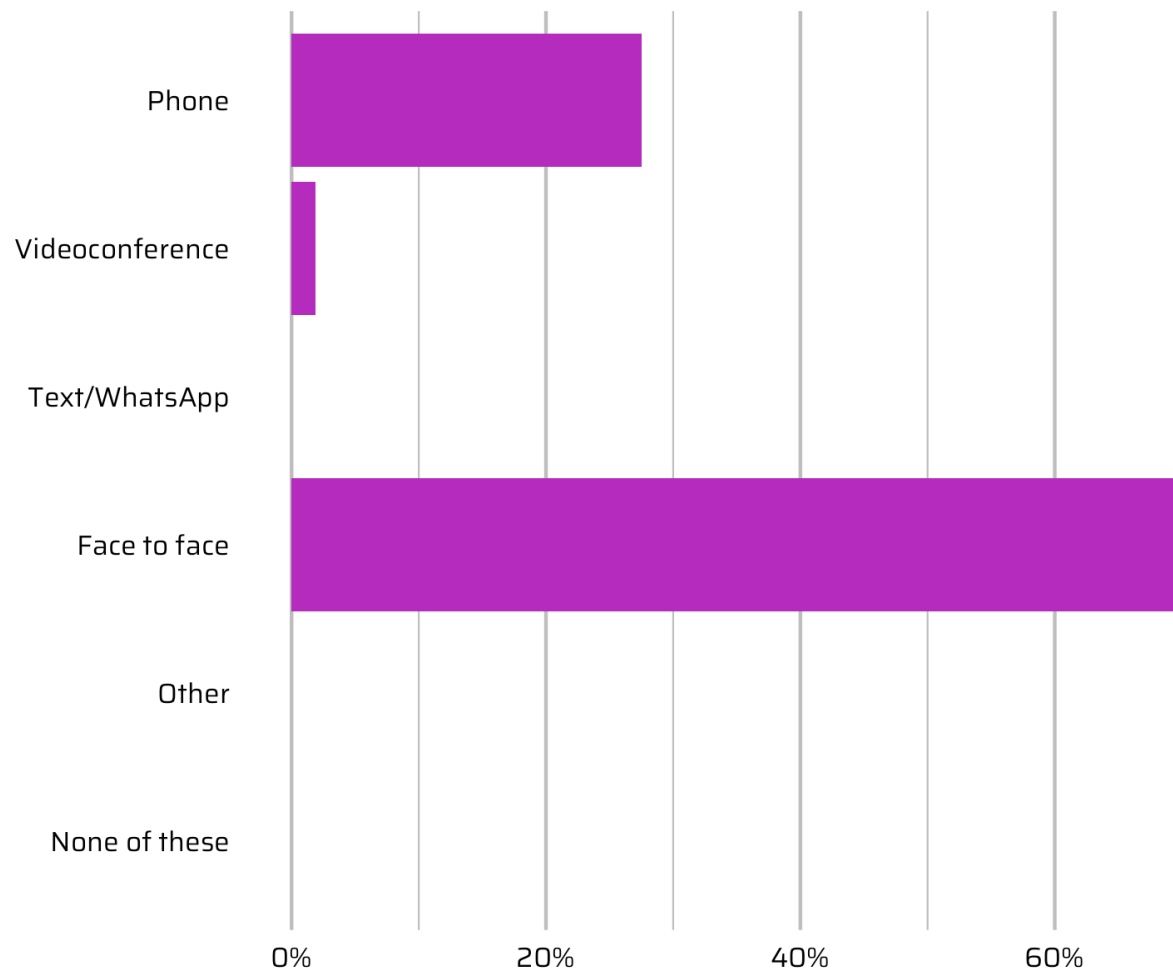


Figure 34: Mode by which medical appointments were delivered.

Table 34: Mode by which medical appointments were delivered.

Mode	Observations	Percentage
Phone	74	28
Videoconference	5	2
Text/WhatsApp	0	0
Face to face	188	70
Other	0	0
None of these	0	0
NA	2	1

Mode of Delivery: Helpfulness Medical Appointment

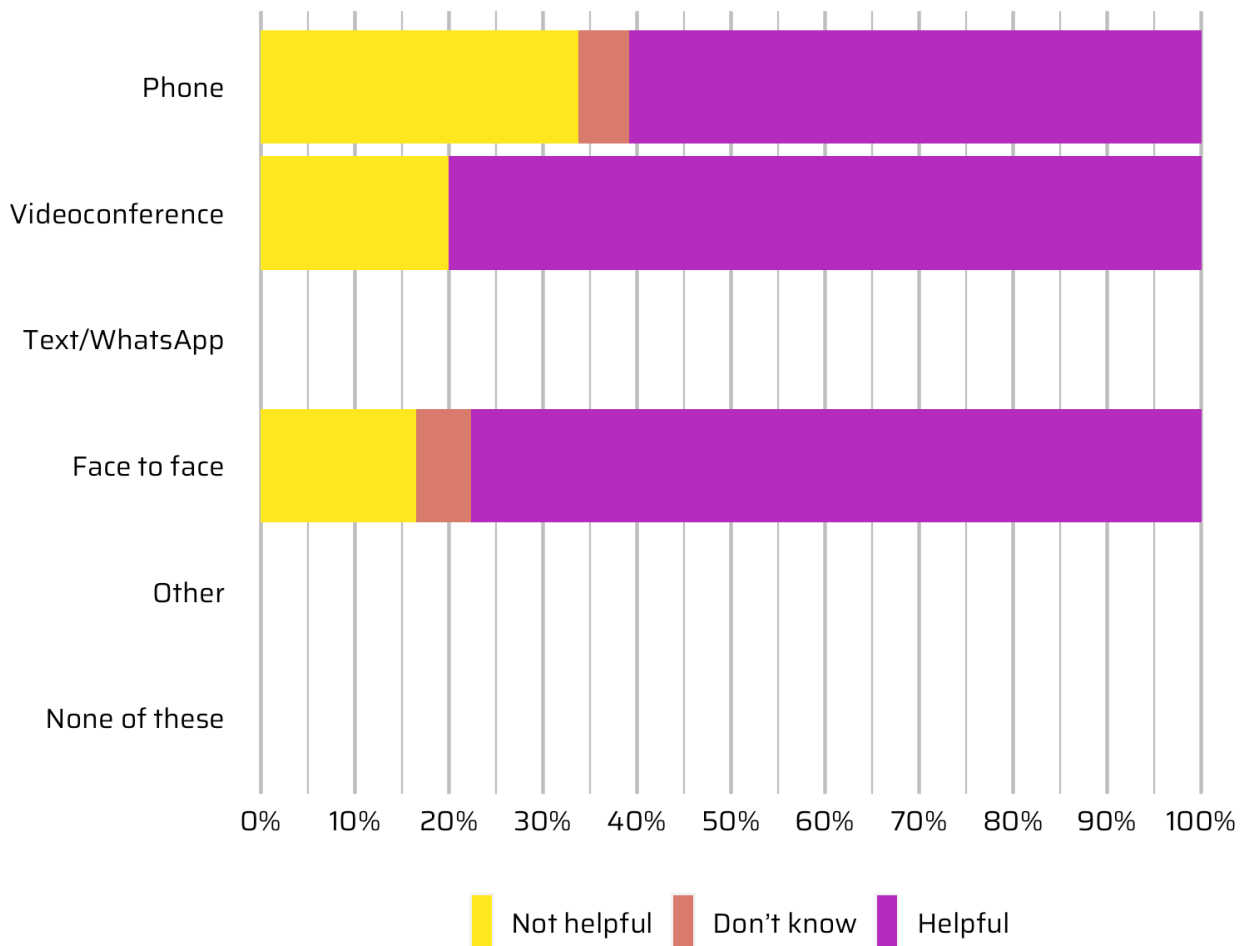


Figure 35: Helpfulness of medical appointment by mode of delivery.

Table 35: Helpfulness of medical appointment by mode of delivery.

Mode	Helpfulness	Observations	Percentage
Phone	Helpful	45	61
Phone	Don't know	4	5
Phone	Not helpful	25	34
Videoconference	Helpful	4	80
Videoconference	Don't know	0	0
Videoconference	Not helpful	1	20
Text/WhatsApp	Helpful	0	NaN
Text/WhatsApp	Don't know	0	NaN

Mode	Helpfulness	Observations	Percentage
Text/WhatsApp	Not helpful	0	NaN
Face to face	Helpful	146	78
Face to face	Don't know	11	6
Face to face	Not helpful	31	16
Other	Helpful	0	NaN
Other	Don't know	0	NaN
Other	Not helpful	0	NaN
None of these	Helpful	0	NaN
None of these	Don't know	0	NaN
None of these	Not helpful	0	NaN
NA	Helpful	1	50
NA	Not helpful	1	50

Demographics of respondents

Sample Size

Total number of respondents: 278

Neurological Conditions

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 147 respondents, equating to 53% of respondents, indicated that they have multiple (i.e., more than one) neurological conditions.

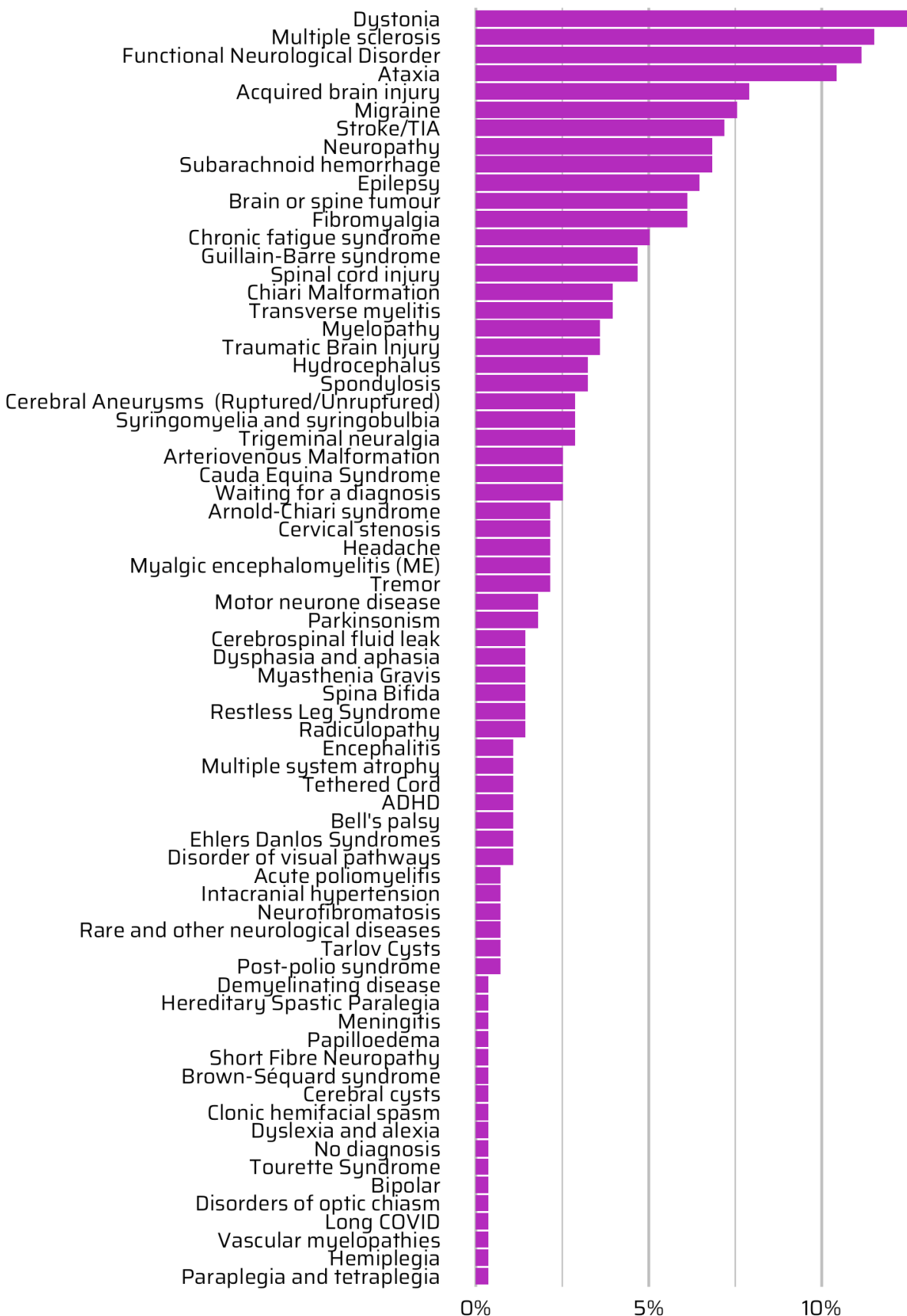


Figure 36: Neurological symptoms and conditions

Table 36: Neurological symptoms and conditions

Condition	Respondents	Percentage
Dystonia	35	13
Multiple sclerosis	32	12
Functional Neurological Disorder	31	11
Ataxia	29	10
Acquired brain injury	22	8
Migraine	21	8
Stroke/TIA	20	7
Neuropathy	19	7
Subarachnoid hemorrhage	19	7
Epilepsy	18	6
Brain or spine tumour	17	6
Fibromyalgia	17	6
Chronic fatigue syndrome	14	5
Guillain-Barre syndrome	13	5
Spinal cord injury	13	5
Chiari Malformation	11	4
Transverse myelitis	11	4
Myelopathy	10	4
Traumatic Brain Injury	10	4
Hydrocephalus	9	3
Spondylosis	9	3
Cerebral Aneurysms (Ruptured/Unruptured)	8	3
Syringomyelia and syringobulbia	8	3
Trigeminal neuralgia	8	3
Arteriovenous Malformation	7	3
Cauda Equina Syndrome	7	3
Waiting for a diagnosis	7	3
Arnold-Chiari syndrome	6	2
Cervical stenosis	6	2
Headache	6	2

Condition	Respondents	Percentage
Myalgic encephalomyelitis (ME)	6	2
Tremor	6	2
Motor neurone disease	5	2
Parkinsonism	5	2
Cerebrospinal fluid leak	4	1
Dysphasia and aphasia	4	1
Myasthenia Gravis	4	1
Spina Bifida	4	1
Restless Leg Syndrome	4	1
Radiculopathy	4	1
Encephalitis	3	1
Multiple system atrophy	3	1
Tethered Cord	3	1
ADHD	3	1
Bell's palsy	3	1
Ehlers Danlos Syndromes	3	1
Disorder of visual pathways	3	1
Acute poliomyelitis	2	1
Intracranial hypertension	2	1
Neurofibromatosis	2	1
Rare and other neurological diseases	2	1
Tarlov Cysts	2	1
Post-polio syndrome	2	1
Demyelinating disease	1	0
Hereditary Spastic Paralegia	1	0
Meningitis	1	0
Papilloedema	1	0
Short Fibre Neuropathy	1	0
Brown-Séquard syndrome	1	0
Cerebral cysts	1	0
Clonic hemifacial spasm	1	0
Dyslexia and alexia	1	0
No diagnosis	1	0

Condition	Respondents	Percentage
Tourette Syndrome	1	0
Bipolar	1	0
Disorders of optic chiasm	1	0
Long COVID	1	0
Vascular myelopathies	1	0
Hemiplegia	1	0
Paraplegia and tetraplegia	1	0

Number of co-occurring non-neurological conditions.

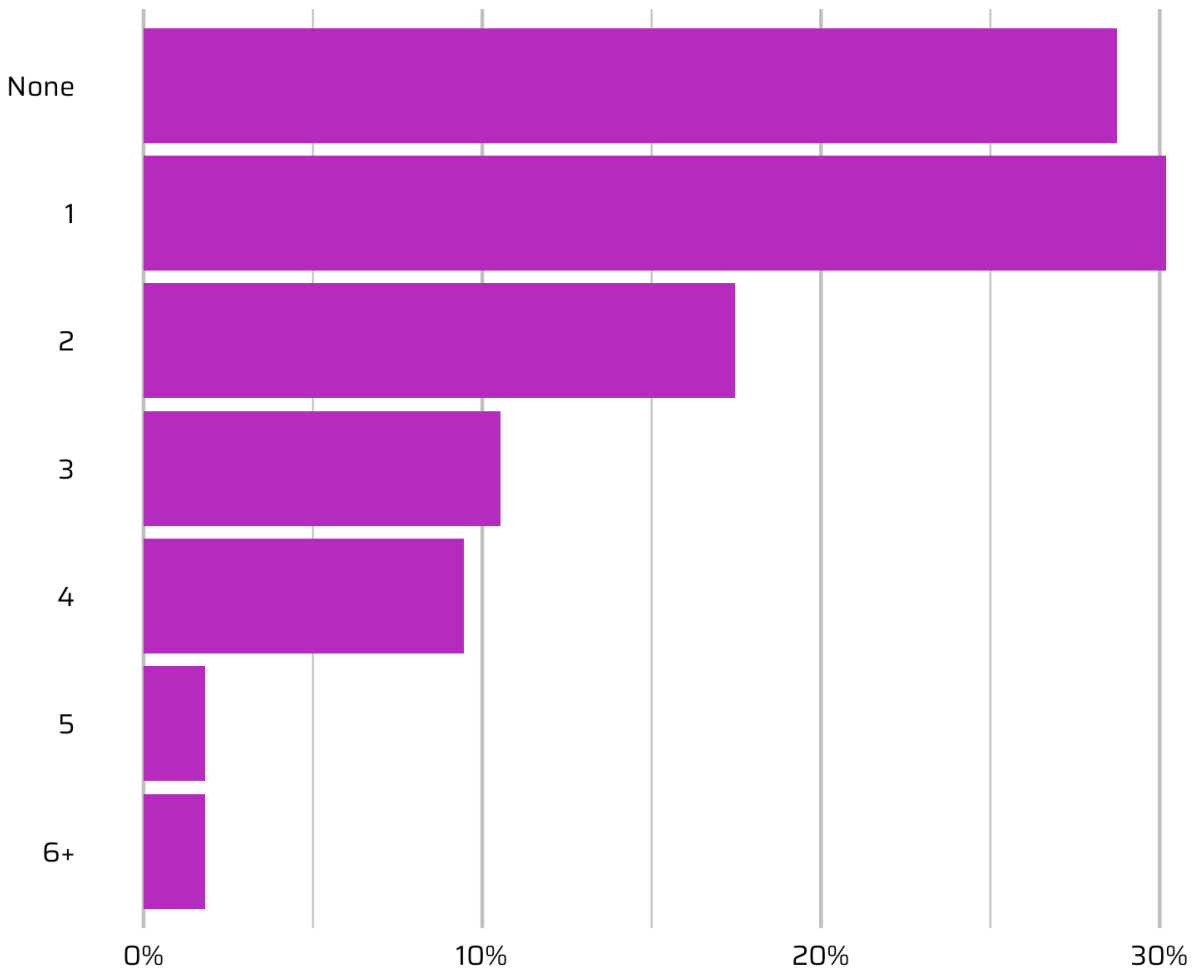


Figure 37: Number of co-occurring non-neurological conditions.

Table 37: Number of co-occurring non-neurological conditions.

Co-occurring Conditions	Respondents	Percentage
None	79	29
1	83	30
2	48	17
3	29	11
4	26	9
5	5	2
6+	5	2

Gender

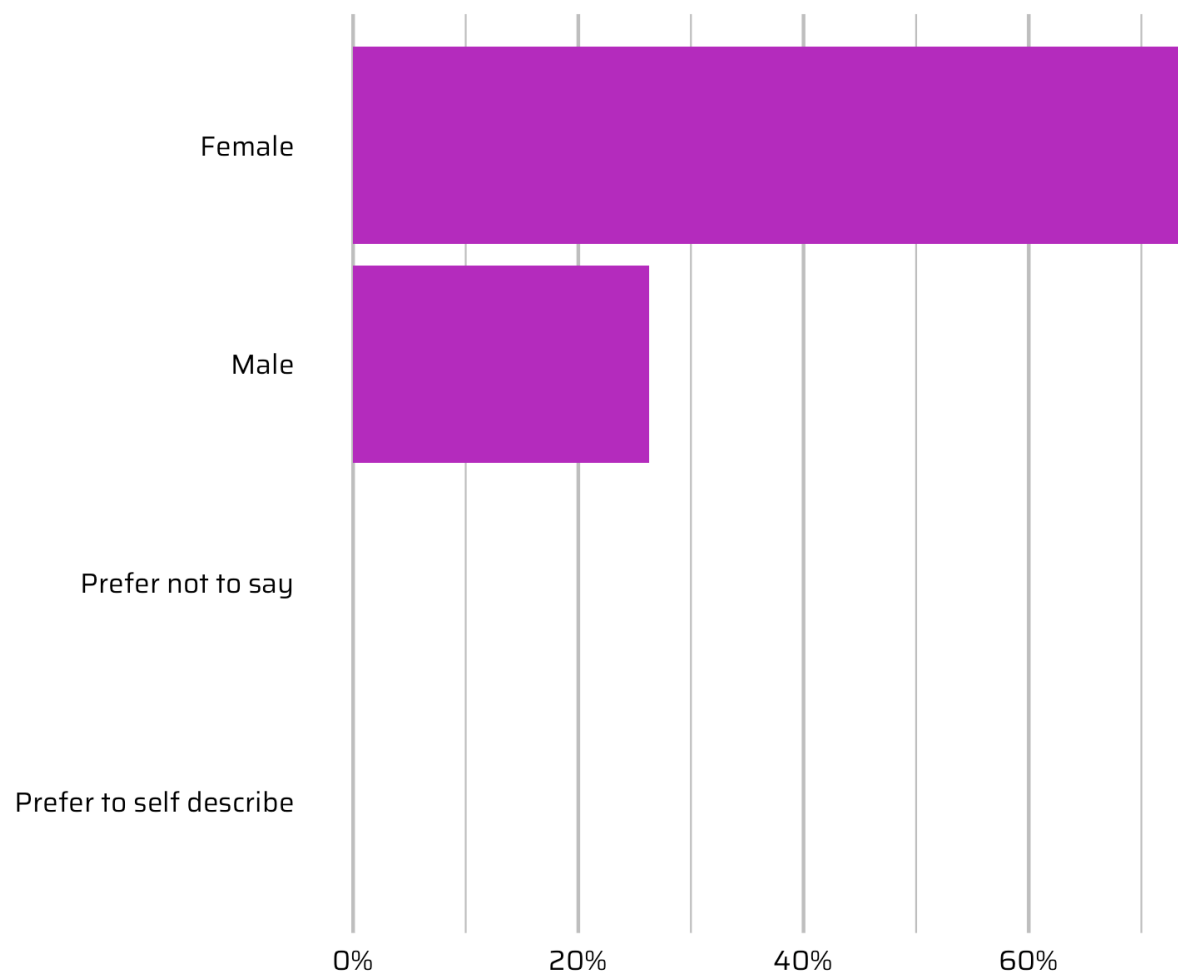


Figure 38: Gender of respondents

Table 38: Gender of respondents

Gender	Respondents	Percentage
Female	205	74
Male	73	26
Prefer not to say	0	0
Prefer to self describe	0	0

Age

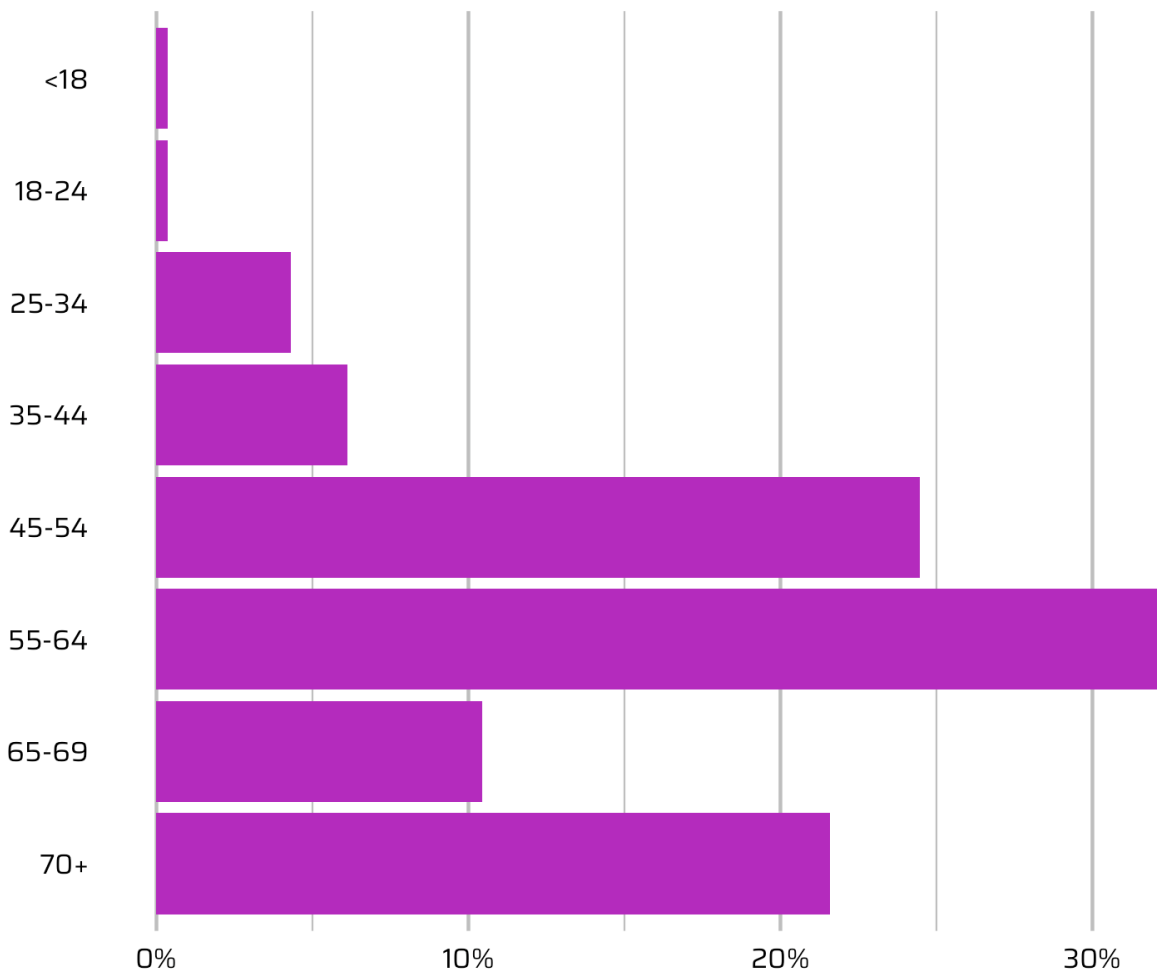


Figure 39: Age of respondents

Table 39: Age of respondents

Age	Respondents	Percentage
<18	1	0
18-24	1	0
25-34	12	4
35-44	17	6
45-54	68	24
55-64	90	32
65-69	29	10
70+	60	22

Age of diagnosis

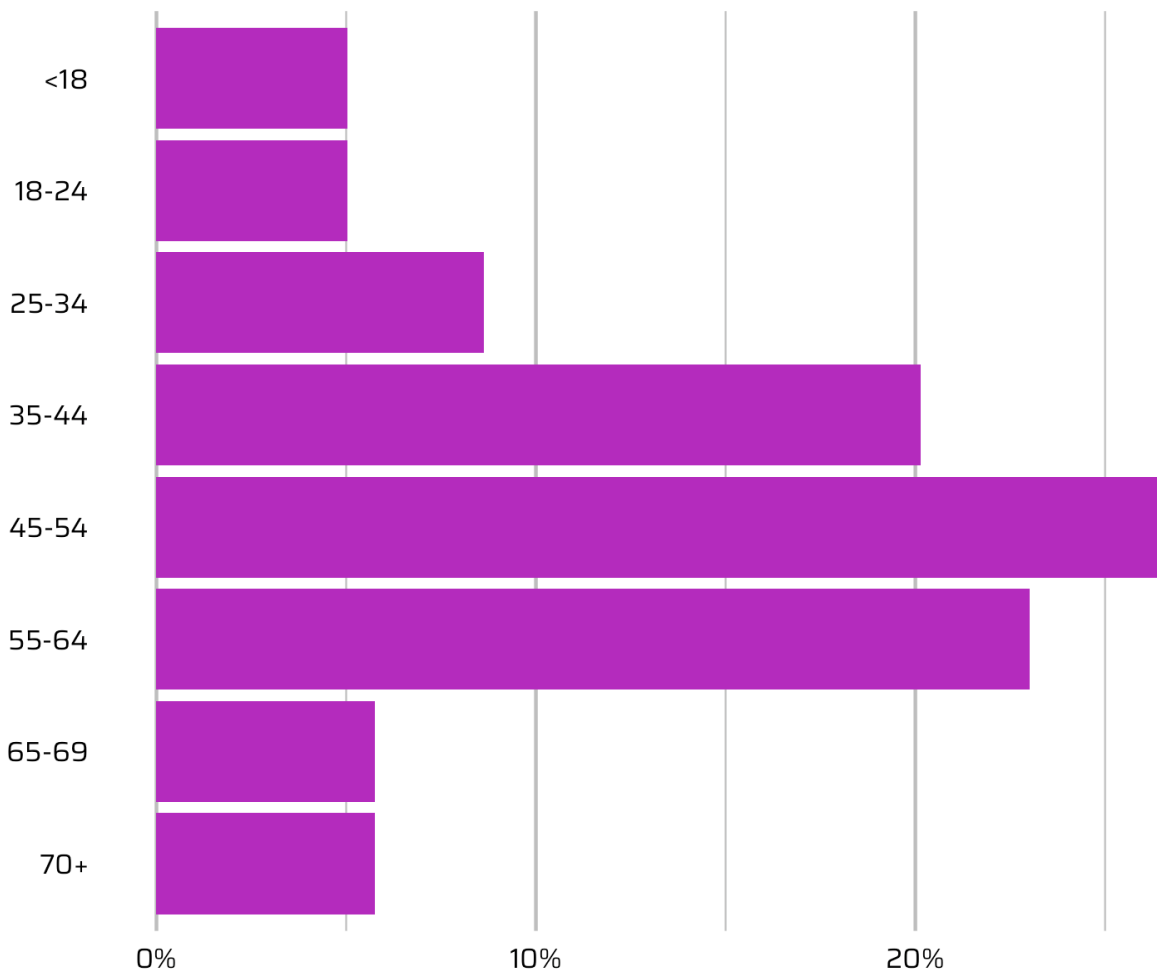


Figure 40: Age of diagnosis

Table 40: Age of diagnosis

Age when diagnosed	Respondents	Percentage
<18	14	5
18-24	14	5
25-34	24	9
35-44	56	20
45-54	74	27
55-64	64	23
65-69	16	6
70+	16	6

Ethnicity

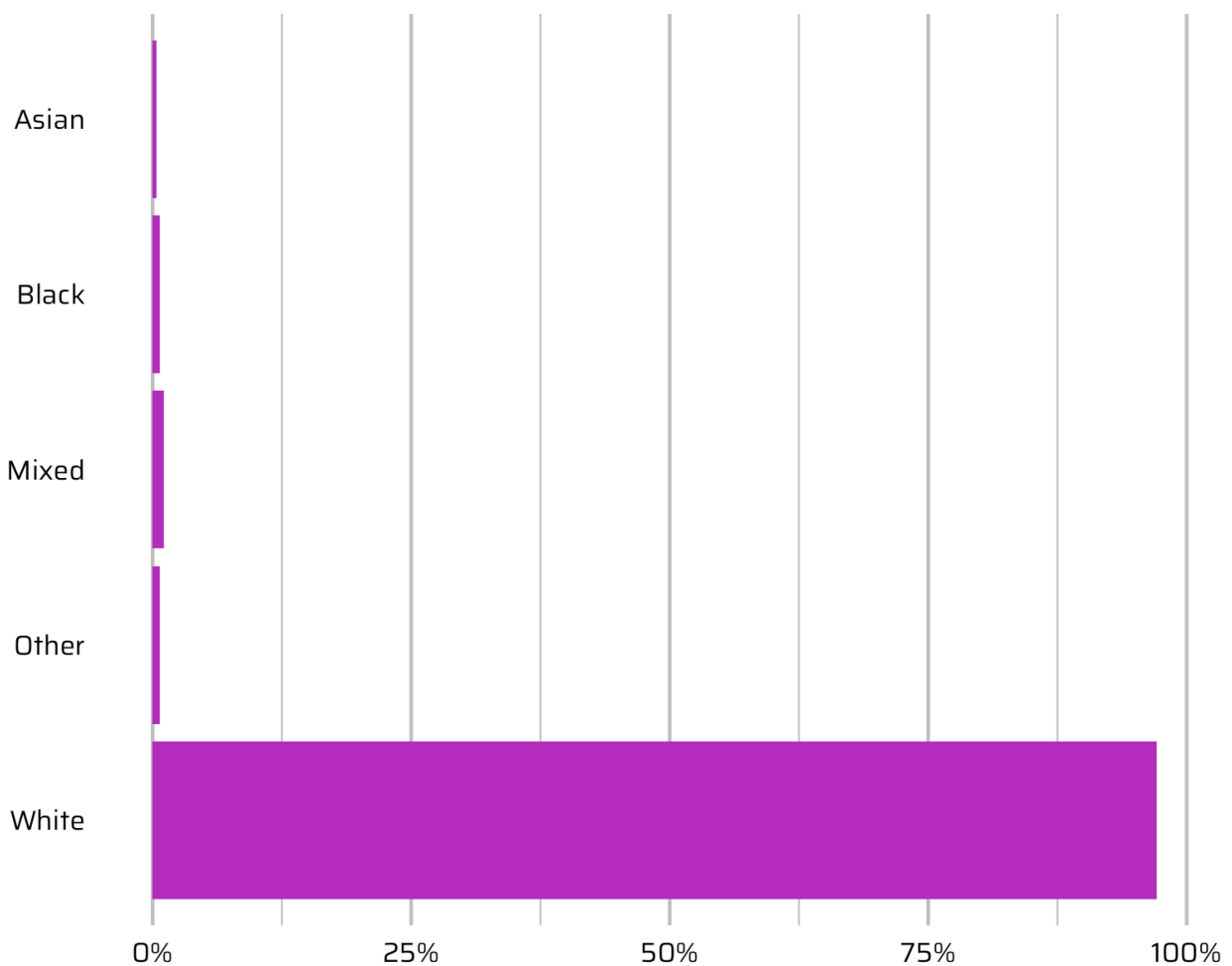


Figure 41: Ethnicity and/or race of respondents.

Table 41: Ethnicity and/or race of respondents.

Ethnicity	Respondents	Percentage
Asian	1	0
Black	2	1
Mixed	3	1
Other	2	1
White	270	97

Location of respondents

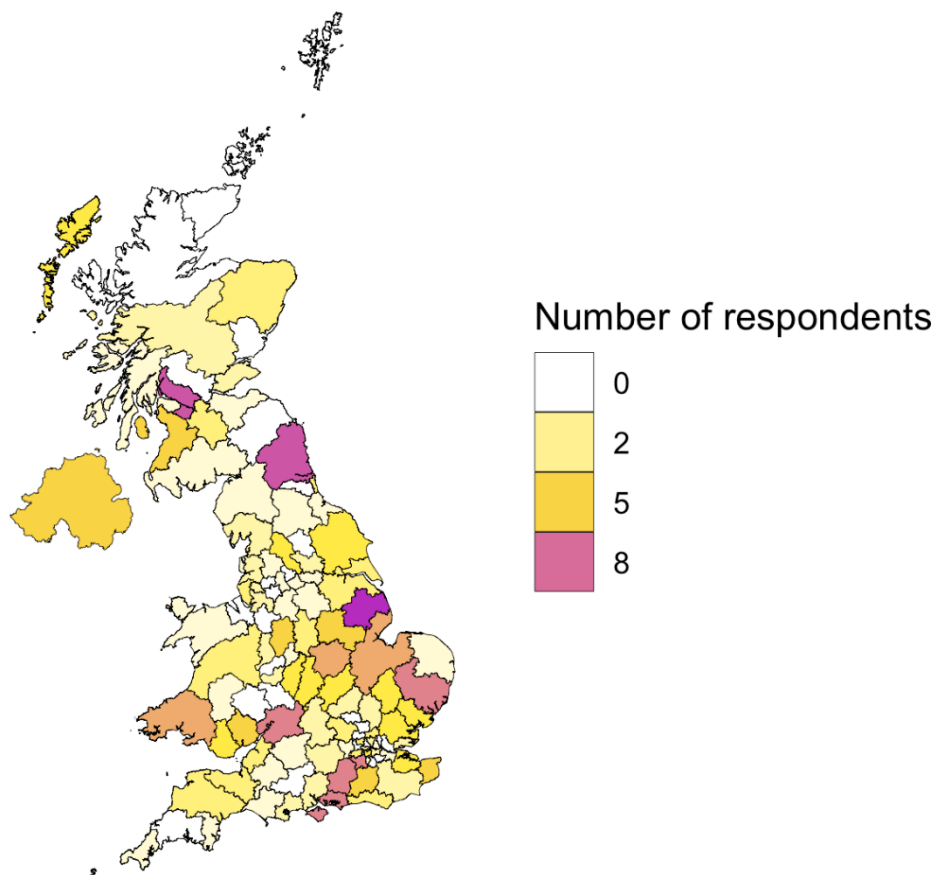


Figure 42: A map showing the number of respondents across the UK based on the postcodes they provided.

Table 42: Number of respondents across the UK based on the postcodes they provided.

Area Name	Postal Area	Number of respondents
Lincoln	LN	9
Glasgow	G	8
Newcastle upon Tyne	NE	8
Gloucester	GL	7
Guildford	GU	7
Ipswich	IP	7
Kingston upon Thames	KT	7
Portsmouth	PO	7
Leicester	LE	6
Peterborough	PE	6
Swansea	SA	6
Canterbury	CT	5
Kilmarnock	KA	5
Nottingham	NG	5
Newport	NP	5
Redhill	RH	5
Stoke-on-Trent	ST	5
Northern Ireland	BT	5
Birmingham	B	4
Bradford	BD	4
Cambridge	CB	4
Cardiff	CF	4
Chelmsford	CM	4
Colchester	CO	4
Coventry	CV	4
Outer Hebrides	HS	4
Medway	ME	4
Northampton	NN	4
London - SW	SW	4
York	YO	4

Area Name	Postal Area	Number of respondents
Aberdeen	AB	3
Brighton	BN	3
Bristol	BS	3
Derby	DE	3
Doncaster	DN	3
Enfield	EN	3
Exeter	EX	3
Harrow	HA	3
Hemel Hempstead	HP	3
Hull	HU	3
Liverpool	L	3
Motherwell	ML	3
Sunderland	SR	3
Shrewsbury	SY	3
Taunton	TA	3
Twickenham	TW	3
Bournemouth	BH	2
Dudley	DY	2
Kirkcaldy	KY	2
Lancaster	LA	2
Leeds	LS	2
Milton Keynes	MK	2
London - N	N	2
Oxford	OX	2
Perth	PH	2
Preston	PR	2
Reading	RG	2
London - SE	SE	2
Stevenage	SG	2
Southampton	SO	2
Southend-on-Sea	SS	2
Telford	TF	2
Tonbridge	TN	2

Area Name	Postal Area	Number of respondents
London - W	W	2
Warrington	WA	2
Wigan	WN	2
Bath	BA	1
Blackburn	BB	1
Carlisle	CA	1
Dartford	DA	1
Dumfries and Galloway	DG	1
Darlington	DL	1
Dorchester	DT	1
London - E	E	1
London - EC	EC	1
Edinburgh	EH	1
The Fylde	FY	1
Huddersfield	HD	1
Llandrindod Wells	LD	1
Llandudno	LL	1
Norwich	NR	1
Oldham	OL	1
Paisley	PA	1
Sheffield	S	1
Stockport	SK	1
Slough	SL	1
Sutton	SM	1
Swindon	SN	1
Torquay	TQ	1
Truro	TR	1
Teeside	TS	1
Wakefield	WF	1
Walsall	WS	1
St Albans	AL	0
Bolton	BL	0
Bromley	BR	0

Area Name	Postal Area	Number of respondents
Chester	CH	0
Croydon	CR	0
Crewe	CW	0
Dundee	DD	0
Durham	DH	0
Falkirk	FK	0
Harrogate	HG	0
Hereford	HR	0
Halifax	HX	0
Ilford	IG	0
Inverness	IV	0
Kirkwall	KW	0
Luton	LU	0
Manchester	M	0
London - NW	NW	0
Plymouth	PL	0
Romford	RM	0
Salisbury	SP	0
Teviotdale	TD	0
Uxbridge	UB	0
London - WC	WC	0
Watford	WD	0
Worcester	WR	0
Wolverhampton	WV	0
Lerwick	ZE	0

NB: Two respondents did not provide a UK-based postcode (e.g., Irish postcode) and are hence not included in the map and table.

Employment Status

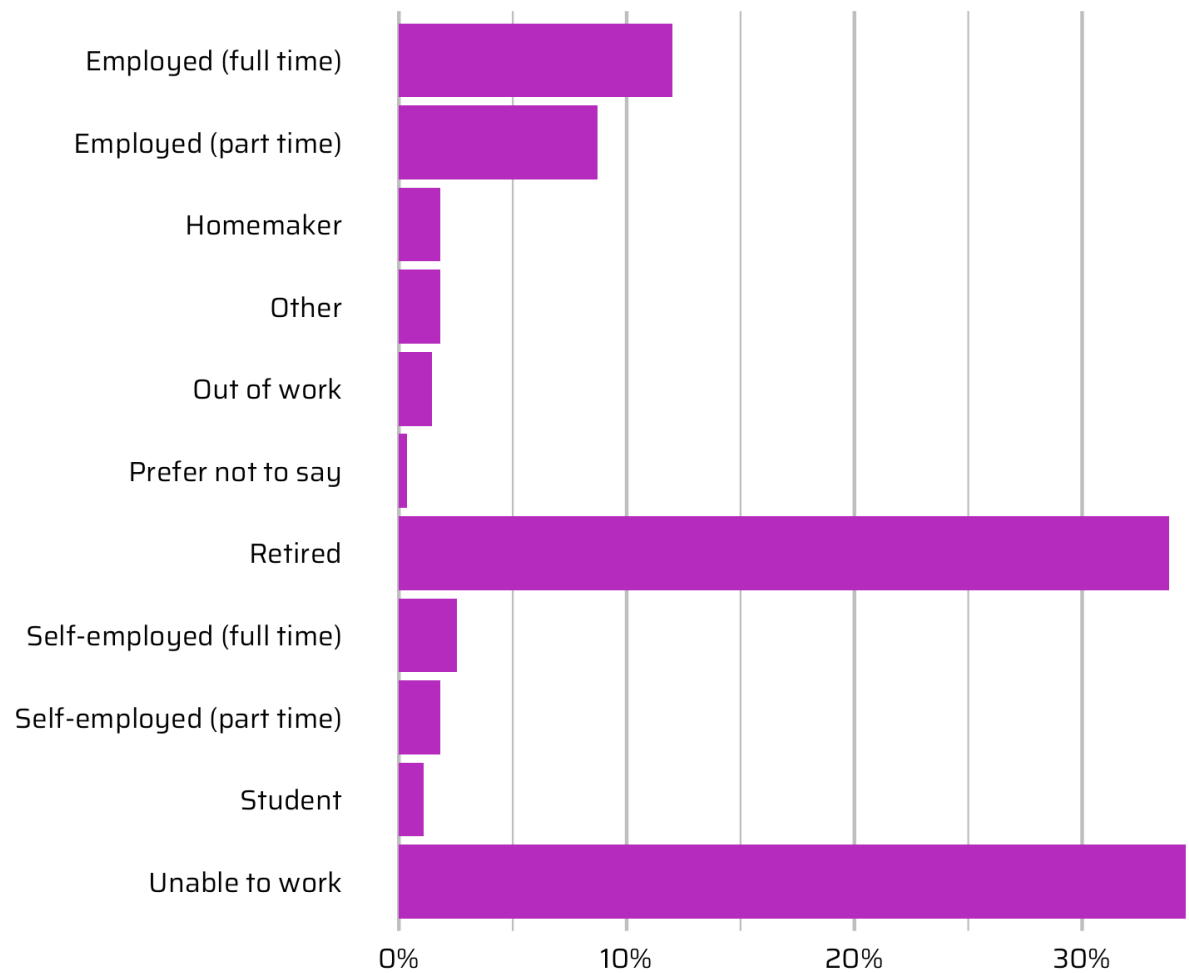


Figure 43: Employment status of respondents.

Table 43: Employment status of respondents.

Employment Status	Respondents	Percentage
Employed (full time)	33	12
Employed (part time)	24	9
Homemaker	5	2
Other	5	2
Out of work	4	1
Prefer not to say	1	0
Retired	93	34
Self-employed (full time)	7	3

Employment Status	Respondents	Percentage
Self-employed (part time)	5	2
Student	3	1
Unable to work	95	35

Financial Status

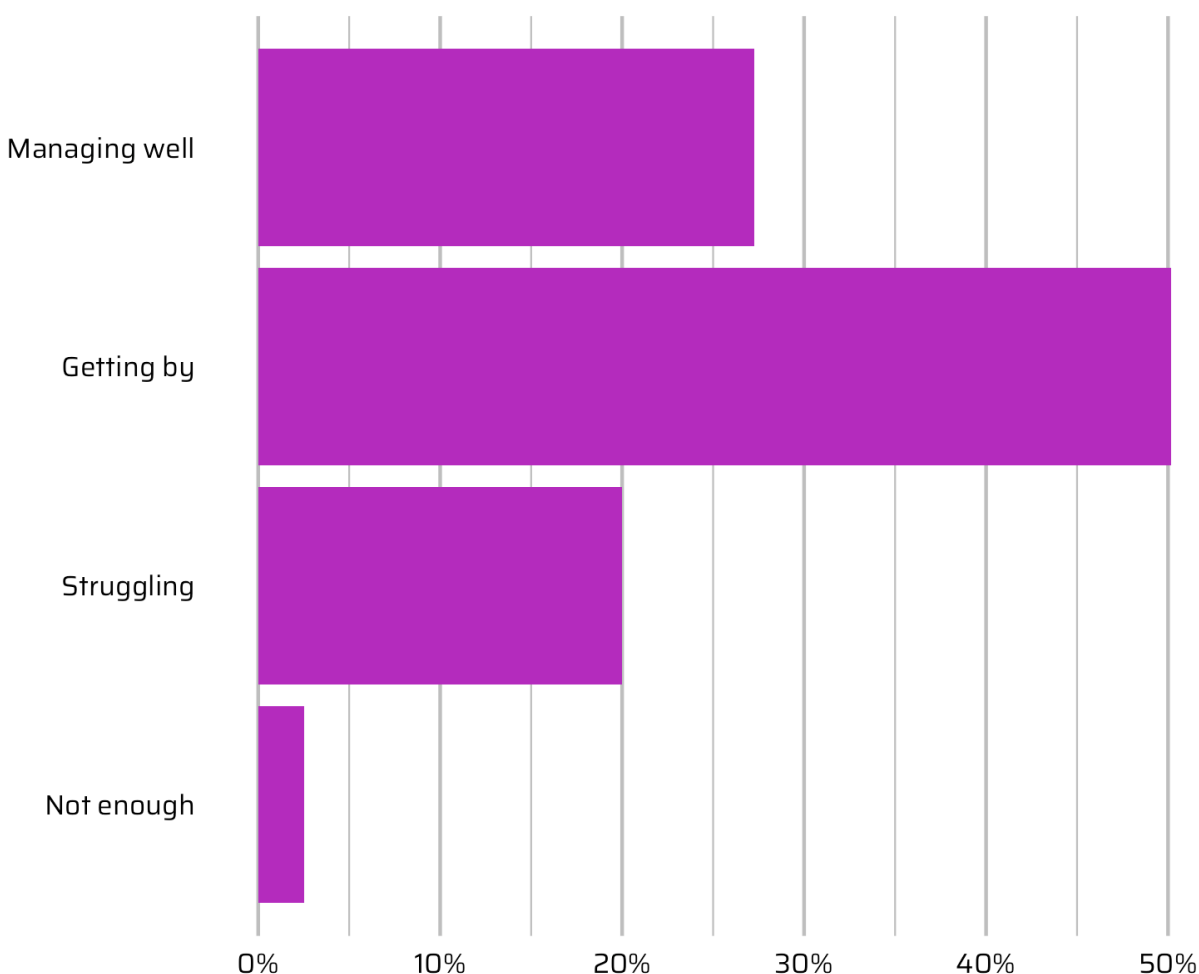


Figure 44: Financial Status of respondents.

Table 44 Financial Status of respondents.

Financial Status	Respondents	Percentage
Managing well	75	27
Getting by	138	50

Financial Status	Respondents	Percentage
Struggling	55	20
Not enough	7	3

Appendix A - Survey Questions

Question	Response options			
Are you filling in this questionnaire for yourself?	Yes	No		
About you, your condition(s) & communicating with you				
Hello, what is your first name?	Free text			
What is your surname?	Free text			
What is your Email Address?	Free text			
What is your postcode?	Free text			
What is your gender?	Male	Female	Prefer to self-describe	Prefer not to say
What year were you born?	Free text			
To which of these ethnic groups do you belong?	White British	White Irish	Any other White background	White and Black Caribbean
	White and Asian	Any other mixed background	Indian	Pakistani
	Bangladeshi	Any other Asian background	Caribbean	African
	Any other Black background	Chinese	Any other ethnic background	
Which year were you diagnosed with your primary neurological condition?	Free text			
Please tell us your first neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms			
Do you have any other neurological condition(s)	Yes	No		

and/or symptoms you would like to add?			
Please tell us a second neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms		
Do you have any other neurological condition(s) and/or symptoms you would like to add?	Yes	No	
Please tell us a third neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms		
Do you have any other neurological condition(s) and/or symptoms you would like to add?	Yes	No	
Please tell us a fourth neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms		
Do you have any other neurological condition(s) and/or symptoms you would like to add?	Yes	No	
Please tell us a fifth neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms		
Do you have any other neurological condition(s) and/or symptoms you would like to add?	Yes	No	
Please tell us a sixth neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms		

Do you live with conditions *other than your neurological condition*(s)? If so, how many:	None	1	2	3
	4	5	6+	
What best describes your employment status?	Employed (full time)	Employed (part time)	Self-employed (full- time)	Self-employed (part-time)
	Homemaker	Student	Out of work	Unable to work
	Retired	Prefer not to say	Other	
How many dependents live with you?	None	1	2	3
	4	5	6+	
Are you filling in this questionnaire for yourself?	Yes	No		
About your recent experiences of care and support.				
Are there any experiences of health and care services from the last eight weeks that you would like to share with us?	Free text			
Have you accessed health and care services in the past eight weeks?	Yes	No		
Overall, how would you describe your experience of health or care in the last eight weeks?	Very good	Good	Average	Poor
	Very Poor	N/A		
How many times have you sought A&E/emergency support from the NHS *as a result of your neurological condition in the last eight weeks?*	None	1-2 times	3-5 times	5 or more times

Have you had any medical appointments (including remote appointments) in the last eight weeks?	Yes	No	Don't Know	
How many medical appointments have you had *in the last four weeks? *	0	1	2	3
	4	5	6+	
Who was your first medical appointment with?	Neurologist	Specialist Nurse	Physiotherapist	Speech and Language Therapist
	Occupational Therapist	Psychologist/ Psychiatrist	GP	Social Services
	Neurosurgery	Other AHP	Other	
How was your first medical appointment delivered?	Phone	Videoconference	Via text/WhatsApp	Face to face
	Other			
How helpful was your first medical appointment?	It was helpful	It was not helpful	Don't Know	
Who was your second medical appointment with?	Neurologist	Specialist Nurse	Physiotherapist	Speech and Language Therapist
	Occupational Therapist	Psychologist/Psychiatrist	GP	Social Services
	Neurosurgery	Other AHP	Other	
How was your second medical appointment delivered?	Phone	Videoconference	Via text/WhatsApp	Face to face
	Other			
How useful was your second medical appointment?	It was helpful	It was not helpful	Don't Know	
Who was your third medical appointment with?	Neurologist	Specialist Nurse	Physiotherapist	Speech and Language Therapist

	Occupational Therapist	Psychologist/Psychiatrist	GP	Social Services
	Neurosurgery	Other AHP	Other	
How was your third medical appointment delivered?	Phone	Videoconference	Via text/WhatsApp	Face to face
	Other			
How helpful was your third medical appointment?	It was helpful	It was not helpful	Don't Know	
Who was your fourth medical appointment with?	Neurologist	Specialist Nurse	Physiotherapist	Speech and Language Therapist
	Occupational Therapist	Psychologist/Psychiatrist	GP	Social Services
	Neurosurgery	Other AHP	Other	
How was your fourth medical appointment delivered?	Phone	Videoconference	Via text/WhatsApp	Face to face
	Other			
How helpful was your fourth medical appointment?	It was helpful	It was not helpful	Don't Know	
Who was your fifth medical appointment with?	Neurologist	Specialist Nurse	Physiotherapist	Speech and Language Therapist
	Occupational Therapist	Psychologist/Psychiatrist	GP	Social Services
	Neurosurgery	Other AHP	Other	
How was your fifth medical appointment delivered?	Phone	Videoconference	Via text/WhatsApp	Face to face
	Other			
How helpful was your fifth medical appointment?	It was helpful	It was not helpful	Don't Know	
Who was your sixth medical appointment with?	Neurologist	Specialist Nurse	Physiotherapist	Speech and Language Therapist

	Occupational Therapist	Psychologist/Psychiatrist	GP	Social Services
	Neurosurgery	Other AHP	Other	
How was your sixth medical appointment delivered?	Phone	Videoconference	Via text/WhatsApp	Face to face
	Other			
How helpful was your sixth 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 eight weeks?	Yes	No	Don't Know	
Which appointments or procedures have been cancelled?	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		
To what extent do you feel your mental wellbeing needs are being met?	To a great extent	To a moderate extent	To a small extent	Not at all
	Don't Know			
Which of the following describes how you feel at the moment?	Calm	Well supported	Anxious	Hopeless
	Lonely			
About your current financial wellbeing				
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.

Appendix B – List of Neurological Conditions & Symptoms

Acquired brain injury	Hemicranial Corrina	Stroke/TIA
Acute poliomyelitis	Hemiplegia	Subacute sclerosing panencephalitis
ADHD	Hereditary Spastic Paralegia	Subarachnoid hemorrhage
Agnosia	Huntington's disease	Syringomyelia and syringobulbia
Amoebic brain abscess	Hydrocephalus	Tarlov Cysts
Apraxia	Hydromyelia	Tethered Cord
Arnold-Chiari syndrome	Intacranial hypertension	Tourette Syndrome
Arteriovenous Malformation	Intracranial abscess and granuloma	Toxic encephalopathy
Ataxia	Intracranial and intraspinal abscess and granuloma in diseases classified elsewhere	Toxoplasma meningoencephalitis
Bell's palsy	Intracranial and intraspinal phlebitis and thrombophlebitis	Transverse myelitis
Bipolar	Intracranial and intraspinal phlebitis and thrombophlebitis	Traumatic Brain Injury
Brain or spine tumour	Intraspinal abscess and granuloma	Tremor
Brown-Séquard syndrome	Kennedy's disease	Trigeminal neuralgia
Cauda Equina Syndrome	Leukoencephalitis	Tuberculous meningitis
Cavernoma	Long COVID	Vascular myelopathies

Cerebral Aneurysms (Ruptured/Unruptured)	Malaria	Waiting for a diagnosis
Cerebral cysts	Melkersson's syndrome	Postzoster neuralgia
Cerebrospinal fluid leak	Meningeal tuberculoma	Progressive multifocal leukoencephalopathy
Cervical stenosis	Meningitis	Rabies
Chagas' disease	Migraine	Radiculopathy
Charcot-Marie-Tooth Disease	Motor neurone disease	Rare and other neurological diseases
Chiari Malformation	Multiple sclerosis	Rare and other neurological diseases
Chronic fatigue syndrome	Multiple system atrophy	Refsum's Disease
Clonic hemifacial spasm	Muscular dystrophy	Restless Leg Syndrome
Cranial nerve disorder	Myalgic encephalomyelitis (ME)	Short Fibre Neuropathy
Creutzfeldt-Jakob disease	Myasthenia Gravis	Spina Bifida
Cysticercosis of central nervous system	Mycoses	Spinal cord injury
Dementia	Myelopathy	Spinal muscular atrophy
Demyelinating disease	Myopathy	Split Cord
Disorder of visual pathways	Myositis	Spondylosis
Disorders of hypoglossal nerve	Myotonic disorders	Stroke/TIA
Disorders of multiple cranial nerves	Narcolepsy and cataplexy	Subacute sclerosing panencephalitis

Disorders of olfactory nerve	Nerve palsy	Subarachnoid hemorrhage
Disorders of optic chiasm	Nerve Tumour	Syringomyelia and syringobulbia
Disorders of other specified cranial nerves	Neurofibromatosis	Tarlov Cysts
Disorders of other visual pathways	Neuromyelitis optica	Tethered Cord
Disorders of vagus nerve	Neuropathy	Tourette Syndrome
Disorders of visual cortex	No diagnosis	Toxic encephalopathy
Down's Syndrome	Optic atrophy	Toxoplasma meningoencephalitis
Dysarthria and anarthria	Papilloedema	Transverse myelitis
Dyslexia and alexia	Paraplegia and tetraplegia	Traumatic Brain Injury
Dysphasia and aphasia	Parkinsonism	Tremor
Dystonia	Post-polio syndrome	Trigeminal neuralgia
Eaton-Lambert syndrome	Postzoster neuralgia	Tuberculous meningitis
Ehlers Danlos Syndromes	Progressive multifocal leukoencephalopathy	Vascular myelopathies
Encephalitis	Rabies	Waiting for a diagnosis
Epidemic vertigo	Radiculopathy	Tourette Syndrome
Epilepsy	Rare and other neurological diseases	Toxic encephalopathy
Extradural and subdural abscess	Rare and other neurological diseases	Toxoplasma meningoencephalitis
Extrapyramidal disorder	Refsum's Disease	Transverse myelitis
Facial myokymia	Restless Leg Syndrome	Traumatic Brain Injury

Faetal Alcohol Spectrum Disorders (FASD)	Short Fibre Neuropathy	Tremor
Fibromyalgia	Spina Bifida	Trigeminal neuralgia
Functional Neurological Disorder	Spinal cord injury	Tuberculous meningitis
Geniculate ganglionitis	Spinal muscular atrophy	Vascular myelopathies
Guillain-Barre syndrome	Split Cord	Waiting for a diagnosis
Headache	Spondylosis	