NeuroLifeNow

November-December 2022 report

Brain & Spine Foundation
THE NEUROLOGICAL ALLIANCE
COMMUNITY FUND

Foreword

This winter has undoubtedly been one of the hardest ever for thousands of people affected by neurological conditions across the UK. Last year, you told us how you didn't feel listened to by Government, and that health, care and financial support just weren't available. We asked you at the end of 2022 to tell us how the UK Government could show it was listening – the message was clear – grow and support our health and care workforce, make sure financial support works for people affected by neurological conditions and invest in much needed research.

The UK Government has an unprecedented opportunity to show it is listening to you by ensuring targeted support is available this winter and beyond. It is clear from your responses to the latest NeuroLifeNow questionnaire, that this has never been more needed.

"Stop making the benefit system so adversarial & complicated."

"Education for benefit assessors so we are not constantly made to go through court type hearings after PIP assessors have got so many factors wrong in an assessment. This is truly detrimental to our well being - mental and physical."

The UK Government have uprated many disability benefits in line with inflation. However, this will only come into force in April 2023, leaving many without the support they need now. We, together with charities across the country, have called on the UK Government to provide urgent financial support to people affected by long term conditions.

Of course, many healthcare professionals have been on strike over the winter period, and this looks set to continue in the months ahead. We are increasingly concerned that people with neurological conditions are experiencing cancellations and delays to their care as the strikes continue. Clearly an agreement must be reached, to ensure we are able to retain and grow the health and care workforce now and in the future, and must needed care can continue.

If you need to talk, you can speak to a neuroscience nurse for free by calling **0808 808 1000** (Mon-Fri, 9am – 4pm) or email helpline@brainandspine.org.uk. Thank you so much.

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

Neurolifenow analysis report

November and December 2022 Questionnaire Responses
Published February 2023

Contents

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 November – 31 December 2022.

Key findings

- 248 people shared their experiences in November and December, with 72% female respondents and 27% male.
- 83 different postcode areas were represented in November and December.
- Restless Leg Syndrome, Functional Neurological Disorder (FND) and migraine were the top three neurological conditions to be cited in November and December. 72 different neurological conditions and symptoms were represented in the survey. A total of 139 respondents, equating to 56% of respondents, indicated that they have multiple (i.e. more than one) neurological conditions.
- We asked you how the new UK Government could show it was listening to people affected by neurological conditions – most commonly you asked for an improved healthcare system and access to professionals, more research, improved financial and social social support and increased recognition of neurological conditions.
- 69% interacted with health or care services in November and December. 30% of those who had a health or care appointment found it unhelpful. 47% of appointments reported were with a GP. Speech and language therapists, specialist nurses and physiotherapists were felt to be the most helpful.
- 31% said their experience of healthcare was good or very good, whilst 35% said it was poor or very poor. Those feeling anxious and/or hopeless were more likely to report poor or very poor experience.
- The proportion of appointments being delivered remotely has decreased compared to previous months of NeuroLifeNow – just 57 appointments were delivered by phone, videoconference or text/Whatsapp. However, all videoconference appointments (n=6) were felt to be helpful. 45% of phone appointments were considered unhelpful.
- More than two thirds (68%) said they felt anxious or hopeless.

Qualitative analyses - How could the government show its commitment?

You were asked how the UK Government could show it is committed to improving the lives of people affected by neurological conditions. A word cloud is generated to visualise the key words that you used.

Word cloud

Fig 1: Words used by respondents to the question relating to how the government can show its commitment to improving the lives of people affected by neurological conditions.

Thematic analysis

A thematic analysis was conducted for responses to the above question, and 4 main themes emerged, summarised below:

- **Theme 1: Improve the healthcare system**
  - Clear clinical pathway
  - Good access to healthcare

- Education for health professionals
- Update outdated guidelines
- Increase number of healthcare professionals
- More funding and investment

- **Theme 2: More research**

- **Theme 3: Provide support**
  - Financial support
  - Social, medical, and other support

- **Theme 4: Recognise neurological conditions**
  - Raise awareness about neurological conditions
  - Listen to people with lived experiences
  - Recognise Restless Leg Syndrome (RLS)

Theme 1: Improve the healthcare system

Clear clinical pathway

You wanted to have a clear clinical pathway for diagnosis and treatment. This includes making it easier for doctors to make referrals, having a neurohub pathway, adopting a holistic approach, and having better communication between healthcare providers.We've captured your responses below:

"Create clear pathways for diagnosis of FND…"

"…a swifter referral to a neurologist"

"Improving follow up care , a neuro hub pathway where you can be assessed through your GP practice and get access to discussing your symptoms, fears and progressive symptoms to."

"Connect various healthcare departments. The system is complex and does not cater for people with complex health issues"

"Finding a way that patients, especially older patients, don't get lost in the system."

"Better communication between healthcare providers could improve the lives of the people living with neurological conditions and those who are caring for them"

Better access to healthcare

You wanted to have easier, better and quicker access to healthcare. This includes better access to specialists, medications, scans, face-to-face appointments, routine check-ups/tests, diagnosis, and treatment. You also expressed there is a lack of healthcare access in rural areas.

"Better access to neuropsychologists to support sufferers with adjustment to chronic illness and long term pain."

"Funding for easier access to MRI"

"Medication availability as on a par to the USA"

"Make GP appointments face to face again."

"Quicker appointments, faster diagnosis, and more routine check ups."

"It can feel very isolating in rural and semi rural areas. I never really knew how my improvement was going (only by my own self care and positive attitude). This isn't always easy, it would have been beneficial to chat with someone who has knowledge and time"

Education for health professionals

You pointed out it is important to have education and training for health professionals. You want them to better understand neurological conditions so that they can provide better treatment and reduce feelings of stigma.

"GP's to have a more enhanced understanding of the condition and how to manage it."

"Better education for both patients and GPs generally so that patients can know the treatment they are having is correct and so that GPs can signpost effectively."

"More training for GP's and neuro and non-neuro specialists"

"Better education [for] physios and radiology triage"

"Spend more time to train people in this specialist field… to stop the ignorance of this condition and bring it to the forefront. Just because it can not be seen doesn't mean it does not exist… stop the stigma and help"

Update outdated guidelines

You wanted outdated guidelines to be revamped, be up to date with current research. You also want other treatment options to be considered.

"Keep up to date with the Mayo Clinic, the NHS is out of date."

"Up to date information on NICE"

"To consider opioid therapy when all other drugs have been tried, like they do in the US."

Increase number of healthcare professionals

You also wanted the number of healthcare professionals to be increased. This includes specialist nurses, occupational therapists, physiotherapists, and neurologists. You also mentioned that the number of social care workers should be increased.

"More specialist nurses"

"Make sure enough neurologists with enough time & expertise"

"Appoint more doctors and nurses"

"Increase the number of specialist… Funding for specialist physio and occupational therapist."

More fundings and investments

You also explicitly suggested more funding should be invested into the health and social care system.

"Targeted funding for NHS"

"Increasing higher rate tax to raise more funds for NHS"

"Put more investment into GP services to identify stroke indicators and early symptoms, and invest in early vocational rehabilitation interventions for survivors"

"Put money into primary care and community support so that people can get referred quickly and get the support they need."

Theme 2: More research

You wanted more research for your neurological conditions to be funded and conducted. This includes research into treatment and management options (e.g., alternative treatments and non-invasive treatments), genetics, and medications.

"Fund all recognised treatments with appropriate budgets and research into treatments"

"…increase funding for genetic research"

"Fund specific research into causes, treatments, protocols for diagnosis and treatment"

"Research in to diagnosis and treatment management options."

Theme 3: Provide support

Financial support

You wanted more financial support. The benefit system should be made fairer and more accessible.

"Fatigue is a difficult symptom of lots of neurological conditions but not recognised in PIP asse[ss]ments. This should be changed."

"Support - both financially and practically - should be available, not all neuro conditions are classed as disabilities and may not qualify for cold weather payments etc. So benefit entitlement should be extended and perhaps vouchers for equipment/warm clothing/food should be provided."

"Stop making the benefit system so adversarial & complicated."

"Education for benefit assessors so we are not constantly made to go through court type hearings after PIP assessors have got so many factors wrong in an assessment. This is truly detrimental to our well being - mental and physical"

"To provide help with transport costs as there are many hospital trips and being over an hour away from my hospital it's very expensive and no buses that would get me there. Costs of heating and food are so high. Extra money for support is needed especially in the winter"

"Include people with disabilities in the entitlement to the £650 payment to help with the cost of living crisis as many people with neurological conditions work which excludes them from financial support"

"Having an independent review of the PIP assessment system to take account of the debilitating nature of neurological conditions."

"To ensure PIP increases with cost of living and importantly not to make this a means tested benefit. I did not choose to finish working at age 59 taking an effective £30k decrease in household incomes. But due to a lifetime of saving and a IHR pension I cannot

claim any means tested benefit which is eroding my savings due to using these to support my living needs and also privately fund physio sessions as the waiting time in the NHS is far too long. Without personal funding my conditions would have deteriorated and I would have required A&E and probable hospital admissions via this route."

Social, legal, and other support
You also wanted Government to support through other ways, such as having social care, infrastructures for rehabilitation, accessible public spaces, legal aid, free medications, support groups, email/helpline, and free medical advice.

"Have accessible hydrotherapy pools for adults and children near where they live"

"Provide legal aid and free medication for suffers which these conditions as medication is expensive"

"More attention towards the aftercare and the mental health of the patients is fundamental as it's non existent at the moment."

"Improved access to social care…"

"Have a helpline / email for my condition so I can get a quick question answered without having to wait months for an appointment"

"Support groups especially following a new diagnoses. I was give a link from the consultant to find out more about the condition when diagnosed. You are not in the right place to understand or process the information"

"Provide free medical advice and prescriptions to help us in attempting to live a normal life."

Theme 4: Recognise neurological conditions
Raise awareness about neurological conditions
You want Government to raise awareness about your condition(s) to create an environment with understanding healthcare professionals without stigmas and ignorance. Neurological conditions should be recognised by doctors, but also be acknowledged in work places.

"Giving neurology and neuro conditions a much higher profile than it already has. Recognise that neurological conditions can affect anyone at any age and they're not confined to the elderly or to mental health; more often than not they have nothing to do with geriatrics or psychiatry"

"acknowledge that it is NOT a psychological condition."

"Train doctors to recognise my condition."

"They should be more understandin[g] how it impacts on ones life when you get many sleepless nights which makes one very depressed to the point of what is the point of living"

"By making GP's more aware of these conditions and making them aware of the Consultants who treat them"

"Make it easier to work, for example ensuring employers make reasonable adjustments and use disability leave rather than the punitive "3 strikes and you're out" sickness policies as a blanket policy for all employees despite knowing of debilitating conditions"

Listen to people with lived experiences
You think the government should listen more to people with lived experience of neurological conditions and include their voices in policies and decisions.

"The Government needs to listen to the personal experiences of people living with neurological conditions along with their families and carers. The reality of living with a condition is not as it's written in text books or vocalised in lectures. The understanding of living with a neurological condition for Health and Care Professionals must begin early in education and those affected must contribute to the creation of educational materials and services."

"The Government needs to hear the experiences of those who are living with neurological conditions and the impact neurological conditions affect their day to day lives."

"need to fully commit to major investment with visible and measurable improvements in ALL areas identified in the My Neuro Survey. Those living with neurological conditions must be consulted every step of the way."

Recognise Restless Leg Syndrome (RLS)
Trigger warning: reference to suicide

Some of you also expressed explicitly that RLS should be acknowledged more. This includes raising awareness about it, including this condition in medical training, updating guidelines about its treatment, and conducting more research.

"Restless Legs is poorly understood by most GPs, and treatments are varied. Doctors need to be aware of how my condition affects life radically. It's is so poorly understood that many are living with it with little help or support. Training should be given to doctors, and money spent on research for this horrible illness"

"Ensure that RLS is included in the training schedule for GPs. There is no one in my Gp practice that knows about what to prescribe or how to help….I had to suggest a medication I had read about on a RLS support group on the internet…I sent him a link to the research being done in Europe and America which states that Pramipexole should no longer be the first port of call anymore and which medications could be prescribed he said it was not relevant because it wasn't UK research. RLS ruins lives and marriages"

"In my case, ensure that GPs learn about RLS, and ensure that NICE updates its procedures for dealing with it. What they are currently stipulating will make the condition worse in the majority of cases. Please note, I had to diagnose myself, and had a hard time educating my GP into giving me the treatment that research has found to be the most suitable."

"Train the medical profession in RLS. It isn't taught at medical school or during GP or neurological training. Most patients now have more expert knowledge than their doctors. RLS UK campaign to get it taught was rejected. Doctors in UK are over prescribing dopaminergic drugs and refusing blood tests. They don't recognise common complication of Dopaminergic drugs and give no help to patients trying to withdraw. World experts have stopped prescribing dopamine agonists yet the UK NICE and NHS guidelines still recommend them."

"Why are doctors not trained to know about it and can actually cause more damage. I don't feel my illness is taken seriously, and have become very depressed as a result, even to the point if ending it all…Please can m[o]re attention be given to training and research of this condition before more p[e]ople have to suffer.."

Quantitative Data - Medical appointments

Access to medical appointments in the last 8 weeks
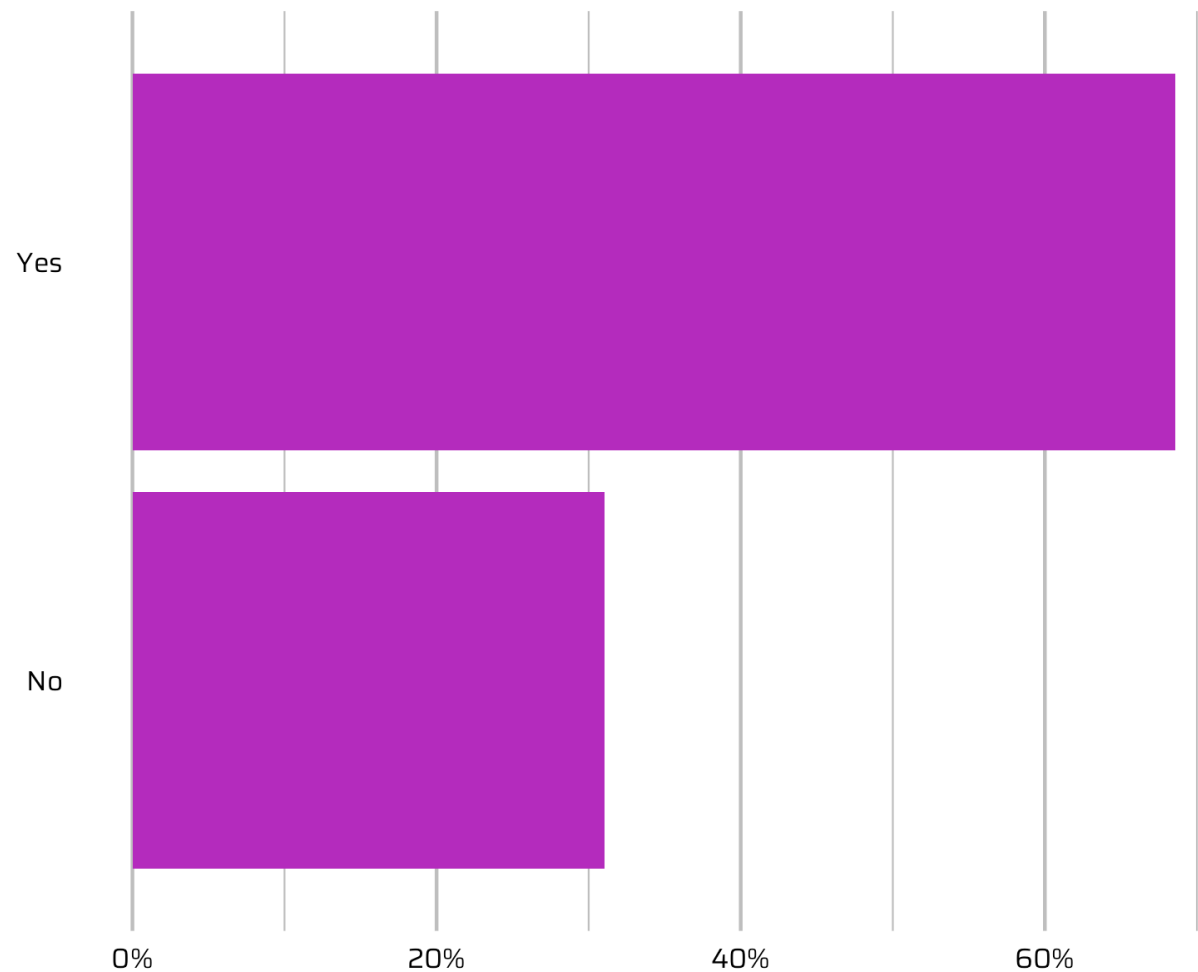
Figure 2: The number of respondents that reported that they have had a medical appointment in the last 8 weeks.

Table 1: The number of respondents that reported that they have had a medical appointment in the last 8 weeks.

Access	Respondents	Percentage
Yes	170	68.55
No	77	31.05

Number of medical appointments in the last 8 weeks.
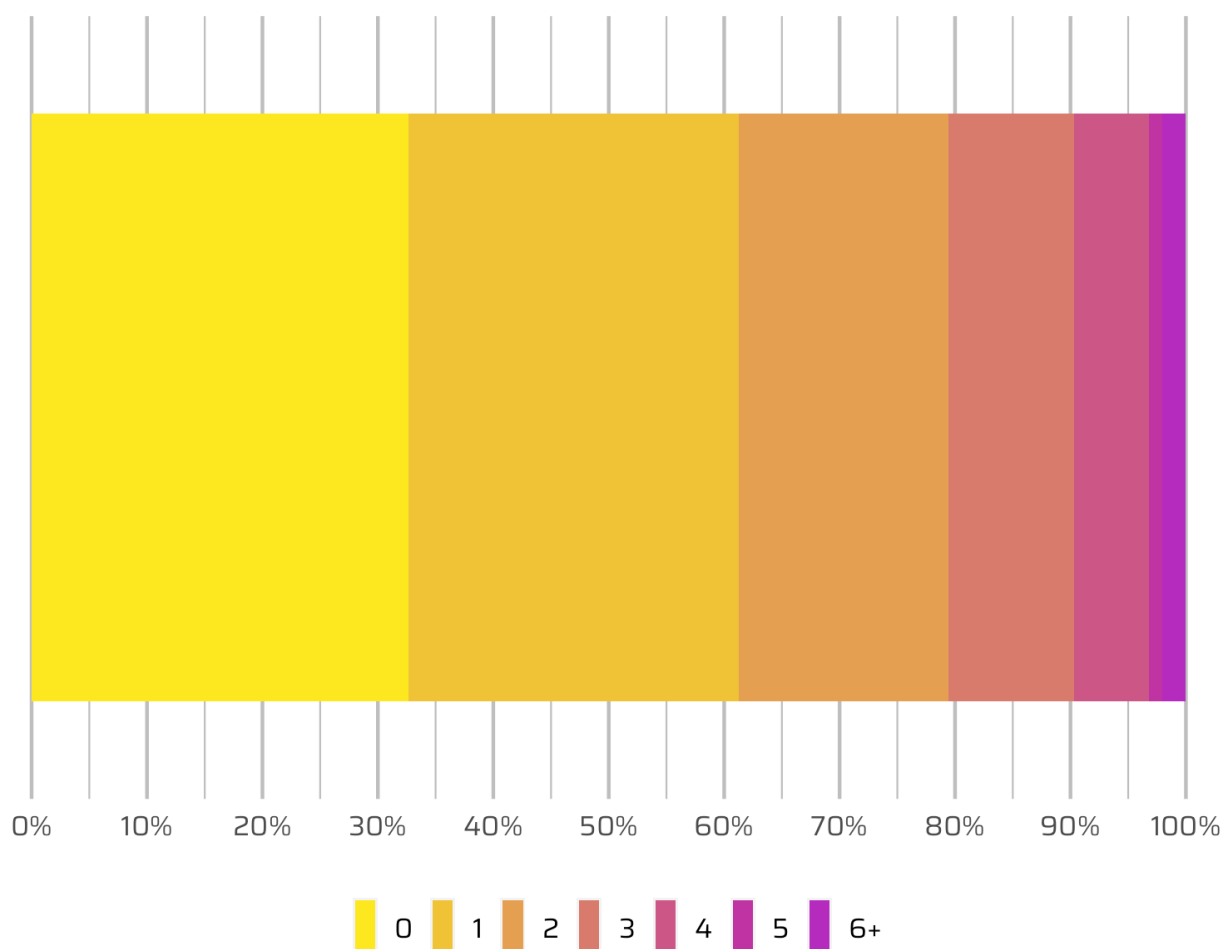
Figure 3: Number of medical appointments in the last 8 weeks.

Table 2: Number of medical appointments in the last 8 weeks.

Number	Respondents	Percentage
6+	5	2.02
5	3	1.21
4	16	6.45
3	27	10.89
2	45	18.15
1	71	28.63
0	81	32.66

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
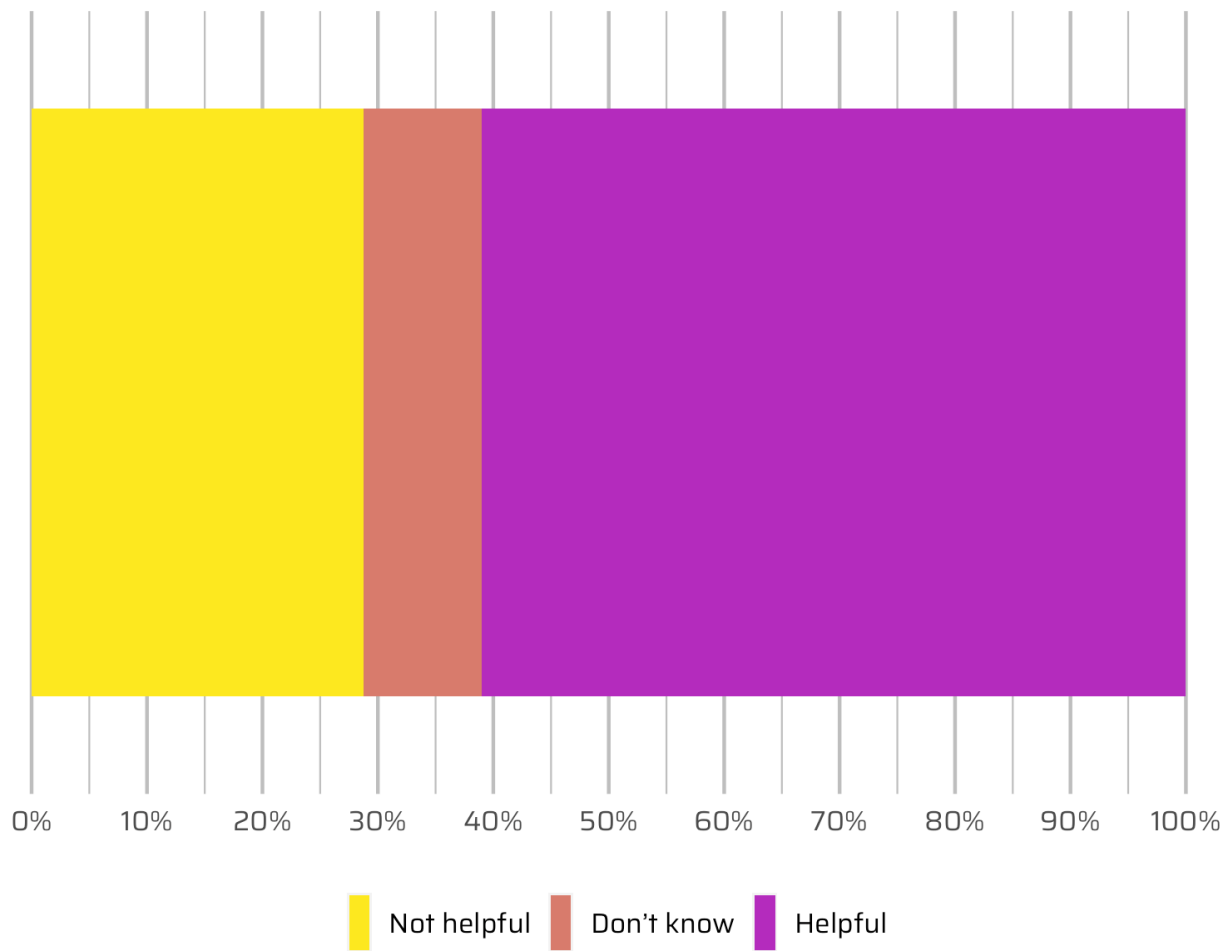
Figure 4:Helpfulness of medical appointments held in the last 8 weeks.

Table 3: Helpfulness of medical appointments held in the last 8 weeks.

Helpfulness	Observations	Percentage
Helpful	225	60.98
Don't know	38	10.30
Not helpful	106	28.73

Specialty of Medical Appointments
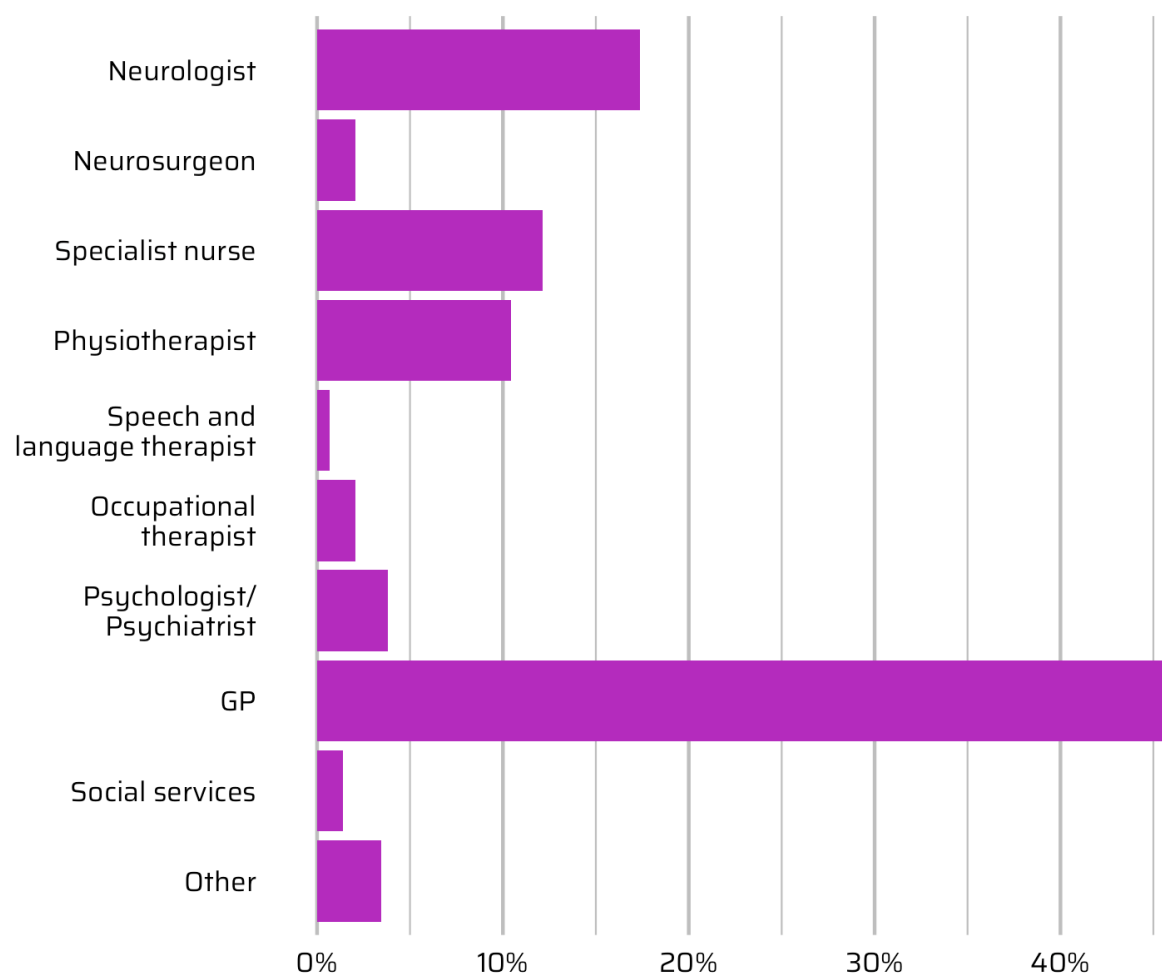
Figure 5: Speciality of the medical appointments held in the last 8 weeks.

Table 4: Speciality of the medical appointments held in the last 8 weeks.

Specialty	Observations	Percentage
Neurologist	50	17.36
Neurosurgeon	6	2.08
Specialist nurse	35	12.15
Physiotherapist	30	10.42
Speech and language therapist	2	0.69
Occupational therapist	6	2.08
Psychologist/Psychiatrist	11	3.82
GP	134	46.53
Social services	4	1.39
Other	10	3.47

Helpfulness of the different medical appointment specialisms
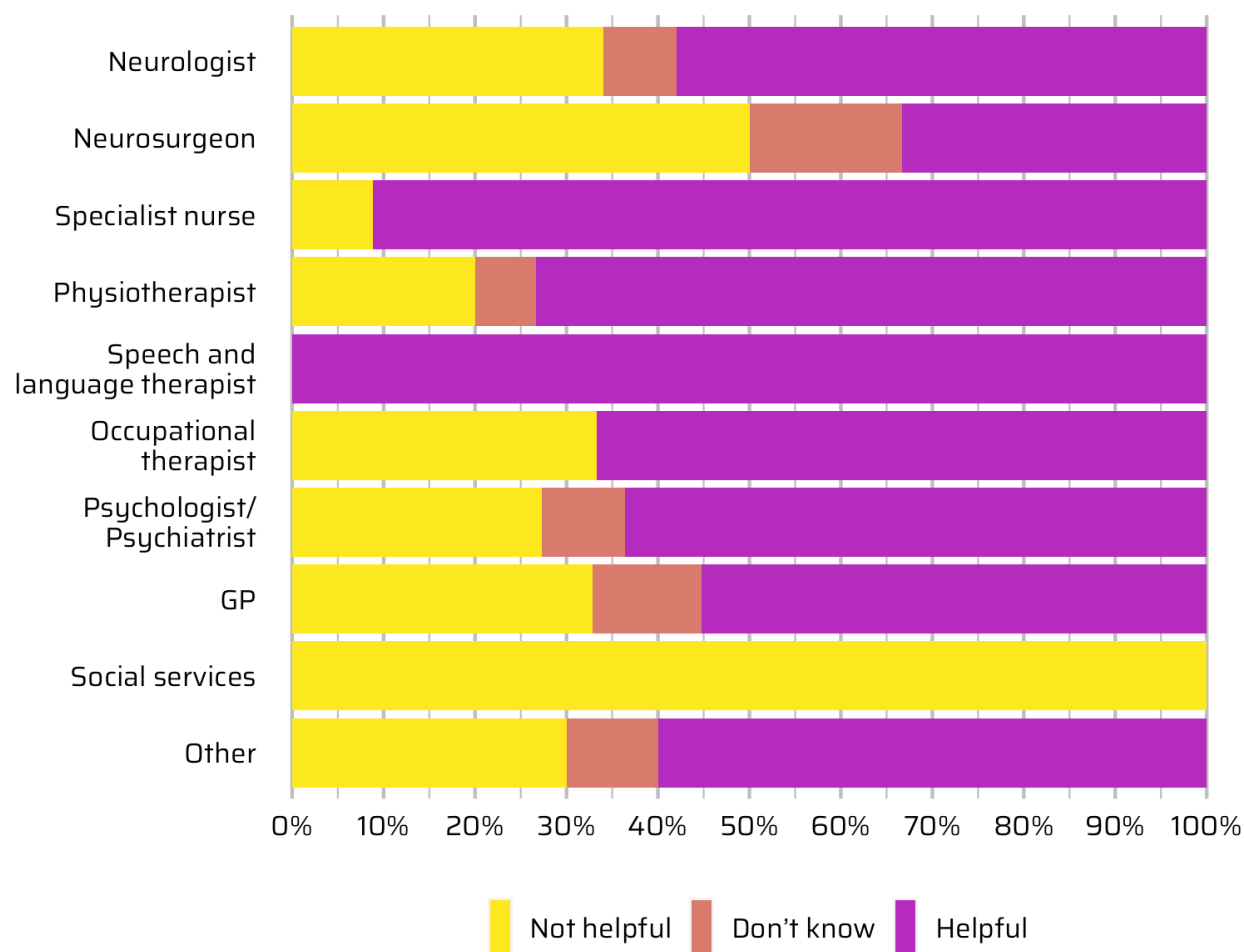
Figure 6: Helpfulness of the different specialiams for medical appointments held in the last 8 weeks.

Table 5: Helpfulness of the different specialiams for medical appointments held in the last 8 weeks.

Specialty	Helpfulness	Observations	Percentage
	Helpful	29	58.00
Neurologist	Don't know	4	8.00
	Not helpful	17	34.00
	Helpful	2	33.33
Neurosurgeon	Don't know	1	16.67
	Not helpful	3	50.00
	Helpful	31	91.18
Specialist nurse	Don't know	0	0.00

Specialty	Helpfulness	Observations	Percentage
	Not helpful	3	8.82
	Helpful	22	73.33
Physiotherapist	Don't know	2	6.67
	Not helpful	6	20.00
	Helpful	2	100.00
Speech and language therapist	Don't know	0	0.00
	Not helpful	0	0.00
	Helpful	4	66.67
Occupational therapist	Don't know	0	0.00
	Not helpful	2	33.33
	Helpful	7	63.64
Psychologist/Psychiatrist	Don't know	1	9.09
	Not helpful	3	27.27
	Helpful	74	55.22
GP	Don't know	16	11.94
	Not helpful	44	32.84
	Helpful	0	0.00
Social services	Don't know	0	0.00
	Not helpful	4	100.00
	Helpful	6	60.00
Other	Don't know	1	10.00
	Not helpful	3	30.00

Mode medical appointments were completed in the last 8 weeks.
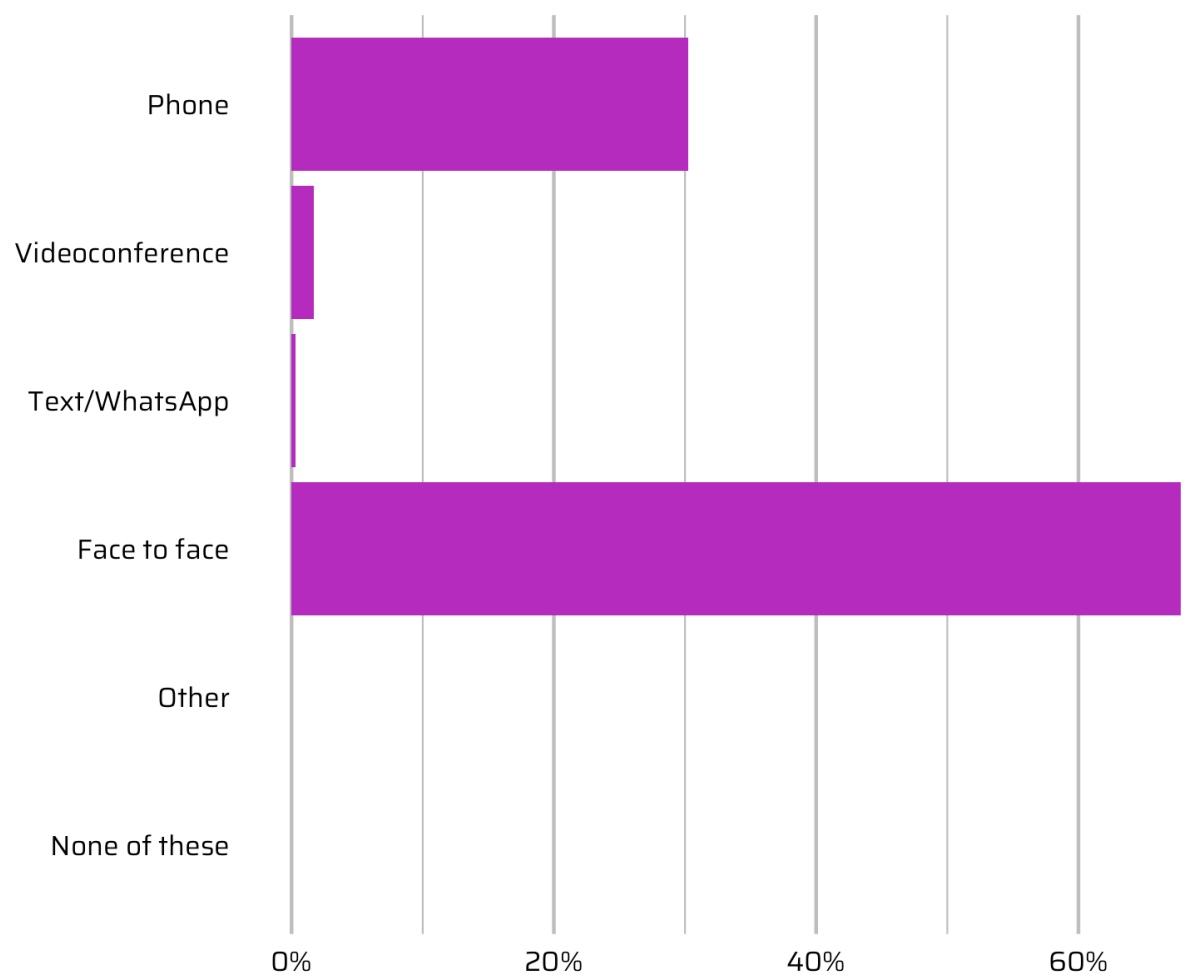
Figure 7: Mode by which medical appointments were held in the last 8 weeks.

Table 6: Mode by which medical appointments were held in the last 8 weeks.

Mode	Observations	Percentage
Phone	108	30.25
Videoconference	6	1.68
Text/WhatsApp	1	0.28
Face to face	242	67.79
Other	0	0.00
None of these	0	0.00

Helpfulness of the different medical appointment modes of delivery.
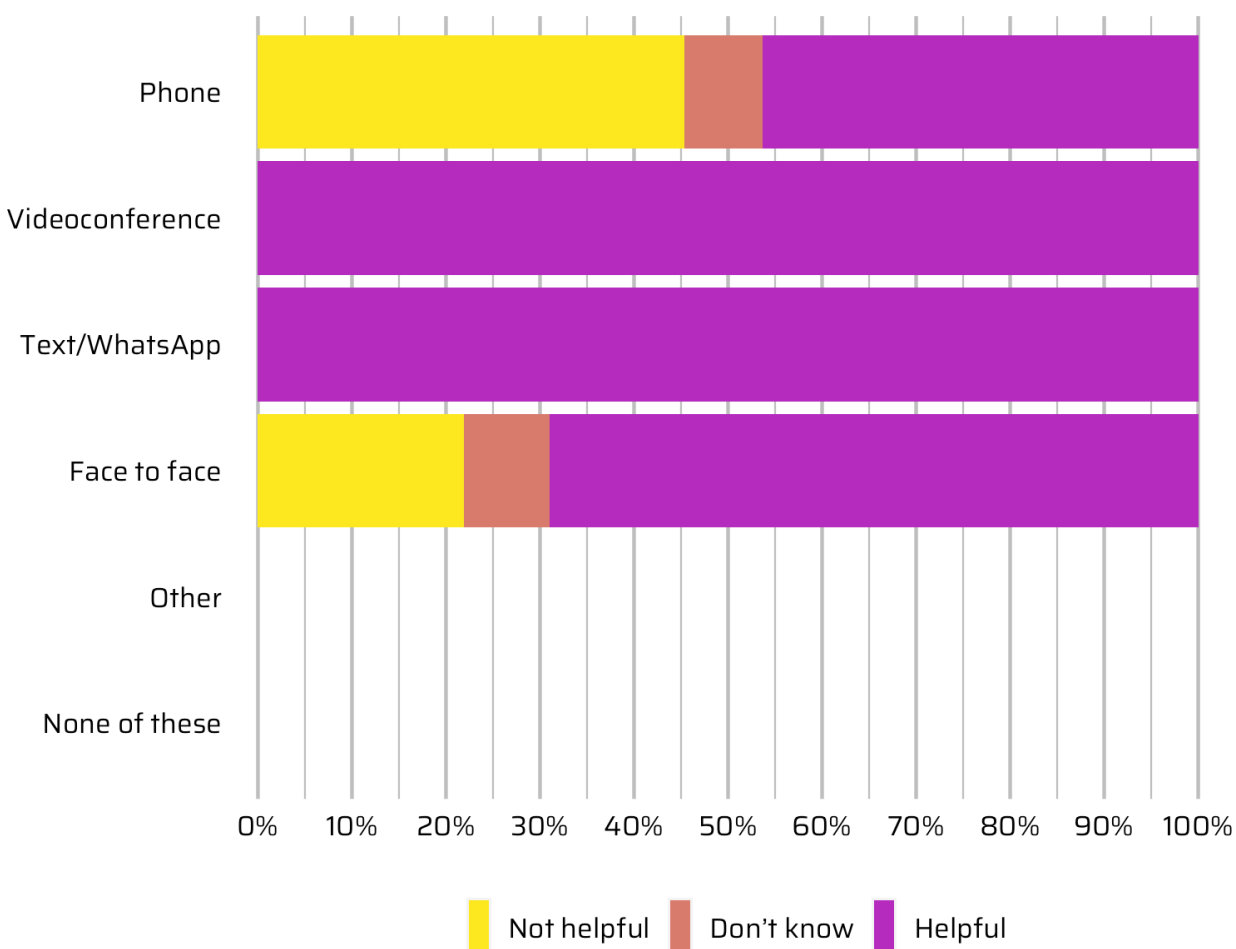
Figure 8: Helpfulness of the different modes of delivery for medical appointments held in the last 8 weeks.

Table 7: Helpfulness of the different modes of delivery for medical appointments held in the last 8 weeks.

Mode	Helpfulness	Observations	Percentage
	Helpful	50	46.30
Phone	Don't know	9	8.33
	Not helpful	49	45.37
	Helpful	6	100.00
Videoconference	Don't know	0	0.00
	Not helpful	0	0.00
Text/WhatsApp	Helpful	1	100.00
	Don't know	0	0.00

Mode	Helpfulness	Observations	Percentage
	Not helpful	0	0.00
	Helpful	167	69.01
Face to face	Don't know	22	9.09
	Not helpful	53	21.90
	Helpful	0	NaN
Other	Don't know	0	NaN
	Not helpful	0	NaN
	Helpful	0	NaN
None of these	Don't know	0	NaN
	Not helpful	0	NaN

Quantitative data - Mental health

Feeling anxious or hopeless
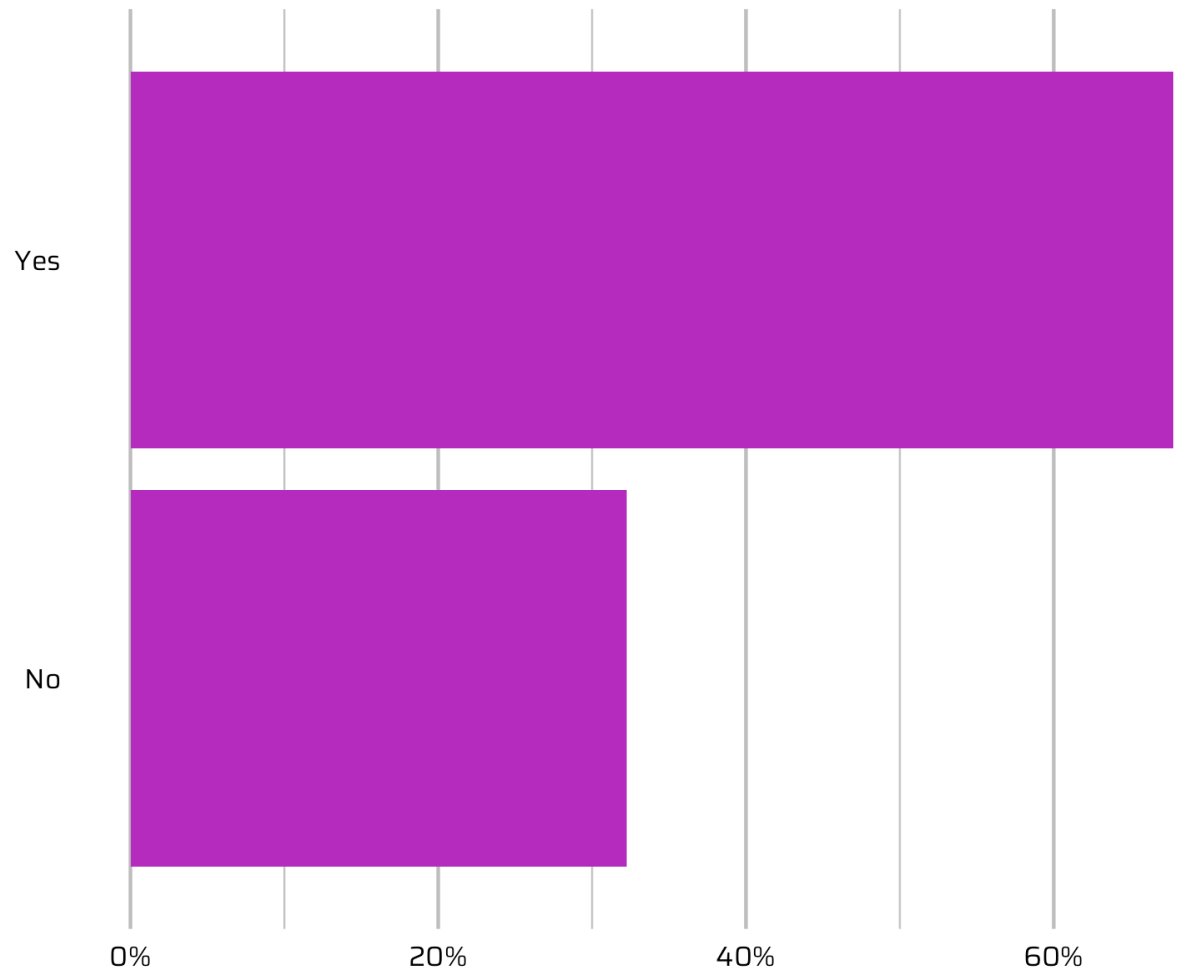
Figure 9: Respondents that reported feeling anxious or hopeless.

Table 8: Respondents that reported feeling anxious or hopeless.

Anxious or Hopeless	Respondents	Percentage
Yes	168	67.74
No	80	32.26

Extent mental health needs are met
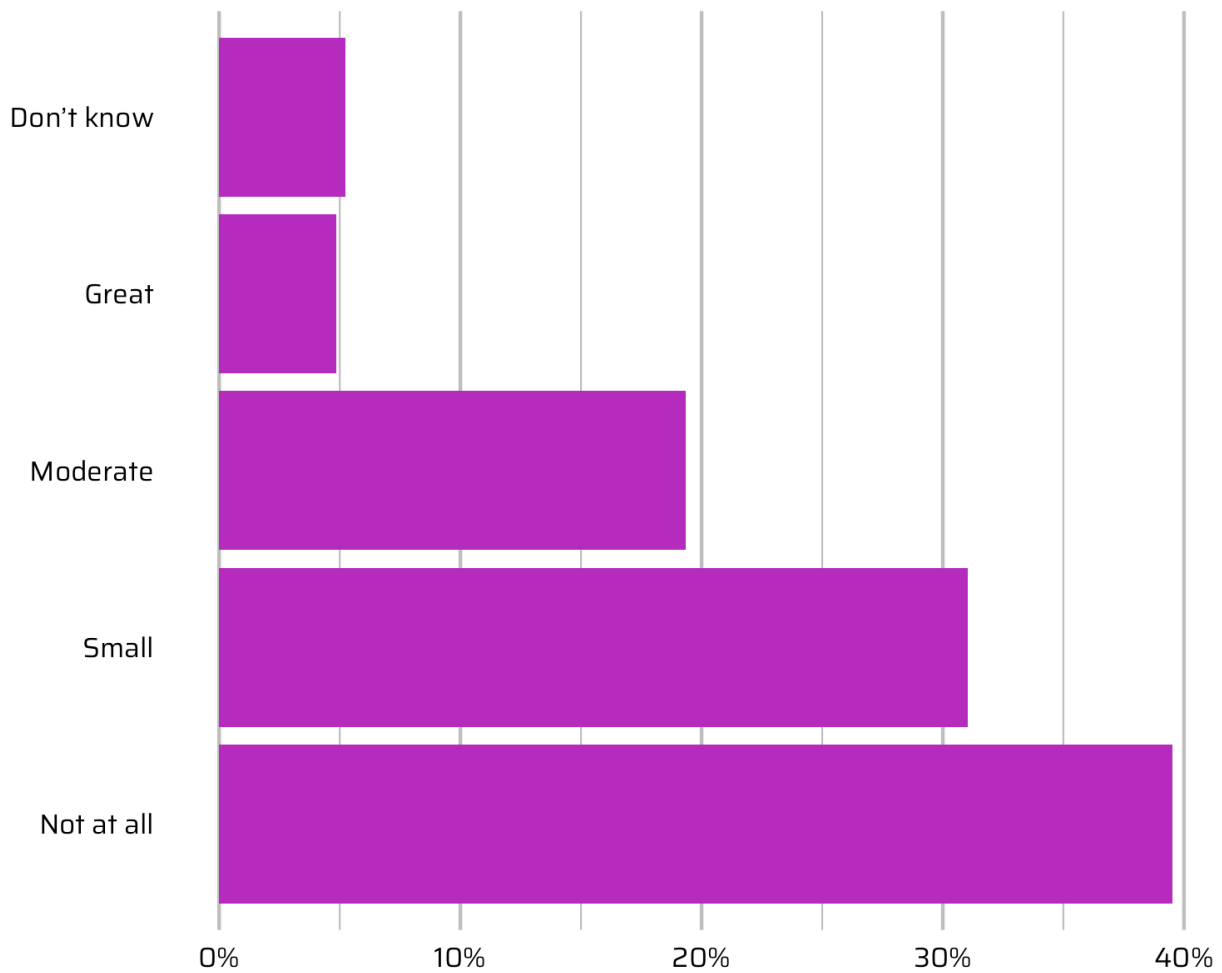
Figure 9: Extent respondents reported their mental health needs were being met.

Table 8: Extent respondents reported their mental health needs were being met.

Extent	Respondents	Percentage
Don't know	13	5.24
Great	12	4.84
Moderate	48	19.35
Small	77	31.05
Not at all	98	39.52

Extent mental health needs met by gender

Figure 10: Extent respondents reported their mental health needs were being met, broken down by gender.

Table 9: Extent respondents reported their mental health needs were being met, broken down by gender.

Gender	Extent	Respondents	Percentage
	Great	6	3.35
	Moderate	31	17.32
Female	Small	59	32.96
	Not at all	73	40.78
	Don't know	10	5.59
	Great	6	8.96
Male	Moderate	17	25.37
	Small	18	26.87

Gender	Extent	Respondents	Percentage
	Not at all	23	34.33
	Don't know	3	4.48
	Great	0	NaN
	Moderate	0	NaN
Prefer not to say	Small	0	NaN
	Not at all	0	NaN
	Don't know	0	NaN
	Great	0	0.00
	Moderate	0	0.00
Prefer to self-describe	Small	0	0.00
	Not at all	2	100.00
	Don't know	0	0.00

Extent mental health needs met by employment status
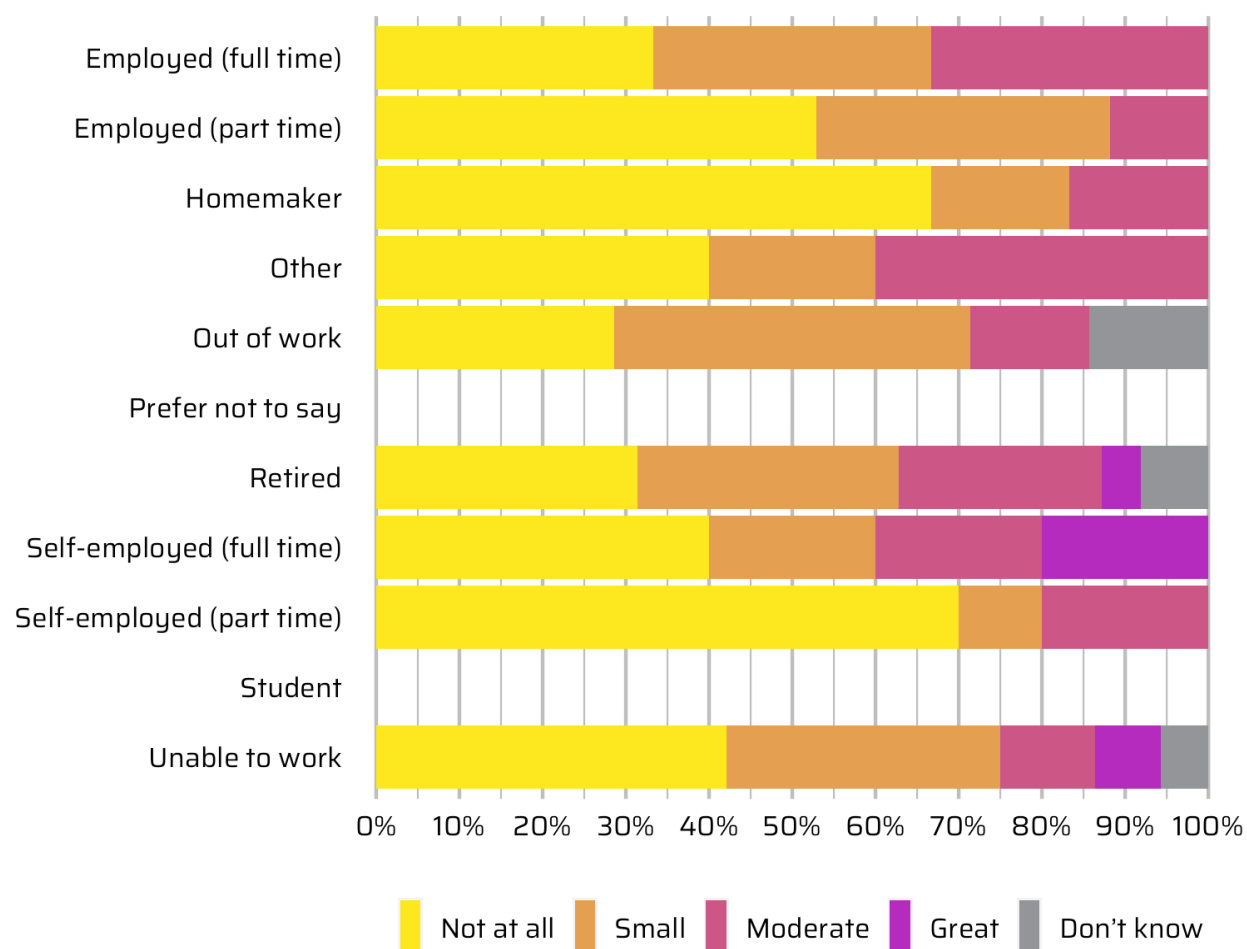
Figure 11: Extent respondents reported their mental health needs were being met, broken down by employment status.

Table 10: Extent respondents reported their mental health needs were being met, roken down by gender.

Employment Status	Extent	Respondents	Percentage
	Great	0	0.00
	Moderate	8	33.33
Employed (full time)	Small	8	33.33
	Not at all	8	33.33
	Don't know	0	0.00
	Great	0	0.00
Employed (part time)	Moderate	2	11.76
	Small	6	35.29

Employment Status	Extent	Respondents	Percentage
	Not at all	9	52.94
	Don't know	0	0.00
	Great	0	0.00
	Moderate	1	16.67
Homemaker	Small	1	16.67
	Not at all	4	66.67
	Don't know	0	0.00
	Great	0	0.00
	Moderate	2	40.00
Other	Small	1	20.00
	Not at all	2	40.00
	Don't know	0	0.00
	Great	0	0.00
	Moderate	1	14.29
Out of work	Small	3	42.86
	Not at all	2	28.57
	Don't know	1	14.29
	Great	0	NaN
	Moderate	0	NaN
Prefer not to say	Small	0	NaN
	Not at all	0	NaN
	Don't know	0	NaN
	Great	4	4.65
	Moderate	21	24.42
Retired	Small	27	31.40
	Not at all	27	31.40
	Don't know	7	8.14
	Great	1	20.00
	Moderate	1	20.00
Self-employed (full time)	Small	1	20.00
	Not at all	2	40.00
	Don't know	0	0.00
	Great	0	0.00
	Moderate	2	20.00
Self-employed (part time)	Small	1	10.00
	Not at all	7	70.00

Employment Status	Extent	Respondents	Percentage
	Don't know	0	0.00
	Great	0	NaN
	Moderate	0	NaN
Student	Small	0	NaN
	Not at all	0	NaN
	Don't know	0	NaN
	Great	7	7.95
	Moderate	10	11.36
Unable to work	Small	29	32.95
	Not at all	37	42.05
	Don't know	5	5.68

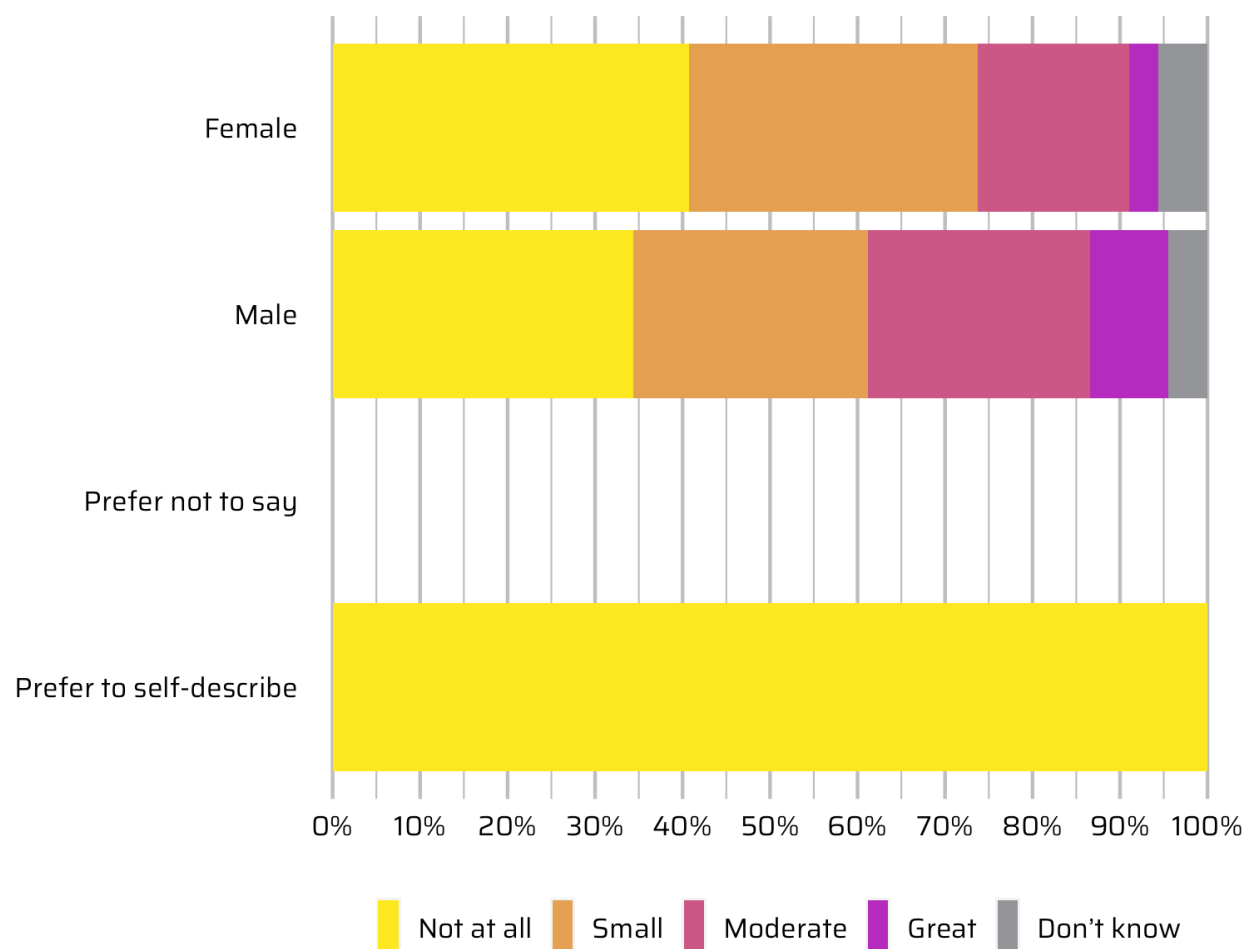## Extent mental health needs met by dependents

Figure 12: Extent respondents reported their mental health needs were being met, broken down by number of dependents.

Table 11: Extent respondents reported their mental health needs were being met, broken down by number of dependents.

Dependents	Extent	Respondents	Percentage
0	Great	10	5.75
	Moderate	32	18.39
	Small	53	30.46
	Not at all	68	39.08
	Don't know	11	6.32
1	Great	2	3.92
	Moderate	9	17.65
	Small	14	27.45
	Not at all	24	47.06
	Don't know	2	3.92
2	Great	0	0.00
	Moderate	5	33.33
	Small	6	40.00
	Not at all	4	26.67
	Don't know	0	0.00
3+	Great	0	0.00
	Moderate	2	25.00
	Small	4	50.00
	Not at all	2	25.00
	Don't know	0	0.00

Extent mental health needs met by feeling anxious or hopeless
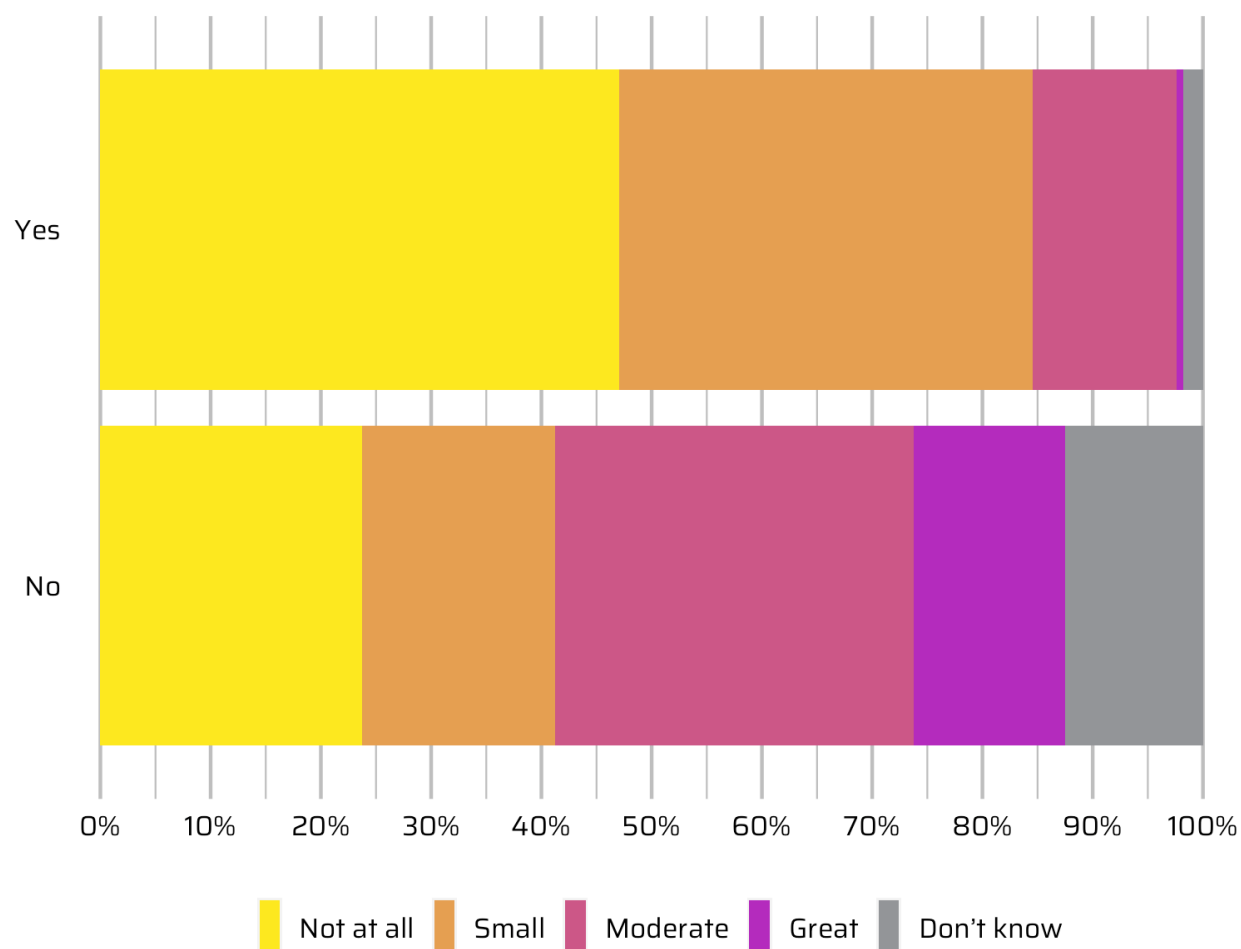
Figure 13: Extent respondents reported their mental health needs were being met, broken down by if they also reported feeling anxious or hopeless.

Table 12: Extent respondents reported their mental health needs were being met, broken down by if they also reported feeling anxious or hopeless.

Anxious or hopeless	Extent	Respondents	Percentage
	Great	1	0.60
	Moderate	22	13.10
Yes	Small	63	37.50
	Not at all	79	47.02
	Don't know	3	1.79
	Great	11	13.75
No	Moderate	26	32.50
	Small	14	17.50

| Anxious or hopeless	Extent	Respondents	Percentage
	Not at all	19	23.75
	Don't know	10	12.50

Extent mental health needs met by age

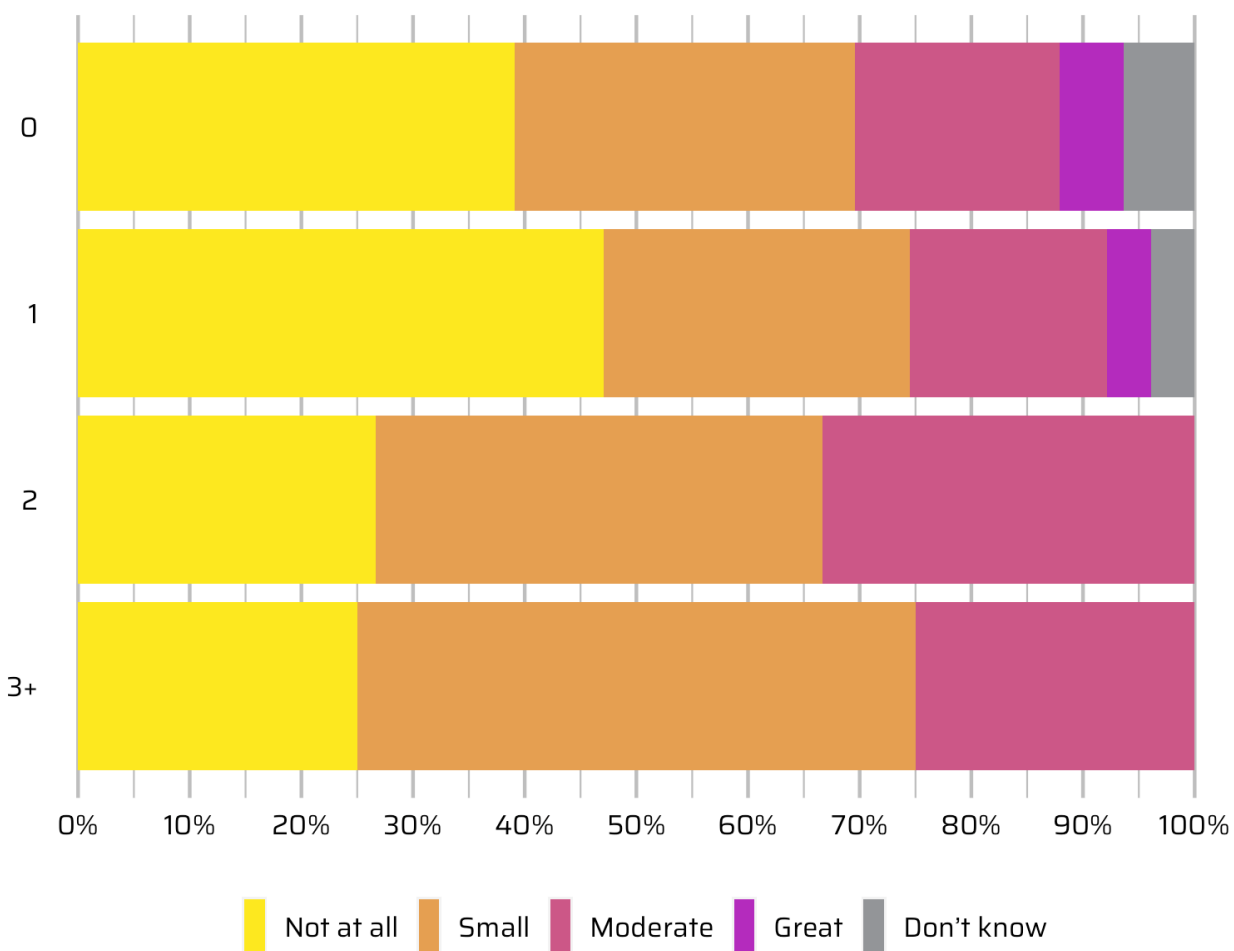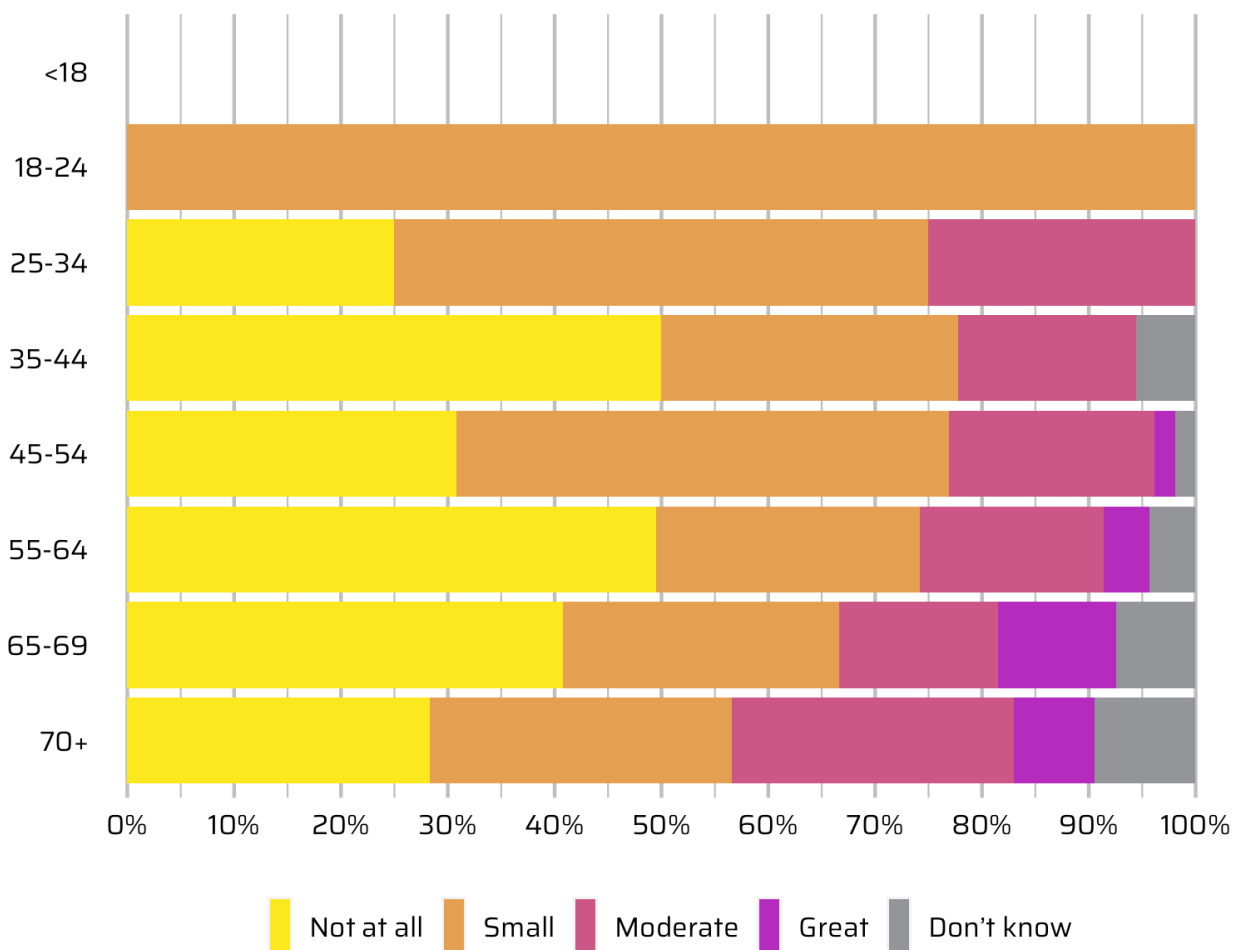*Figure 14: Extent respondents reported their mental health needs were being met, broken down by age group.*

Table 13: Extent respondents reported their mental health needs were being met, broken down by age group.

Age	Extent	Respondents	Percentage
	Great	0	NaN
	Moderate	0	NaN
<18	Small	0	NaN
	Not at all	0	NaN

Age	Extent	Respondents	Percentage
	Don't know	0	NaN
	Great	0	0.00
	Moderate	0	0.00
18-24	Small	1	100.00
	Not at all	0	0.00
	Don't know	0	0.00
	Great	0	0.00
	Moderate	1	25.00
25-34	Small	2	50.00
	Not at all	1	25.00
	Don't know	0	0.00
	Great	0	0.00
	Moderate	3	16.67
35-44	Small	5	27.78
	Not at all	9	50.00
	Don't know	1	5.56
	Great	1	1.92
	Moderate	10	19.23
45-54	Small	24	46.15
	Not at all	16	30.77
	Don't know	1	1.92
	Great	4	4.30
	Moderate	16	17.20
55-64	Small	23	24.73
	Not at all	46	49.46
	Don't know	4	4.30
	Great	3	11.11
	Moderate	4	14.81
65-69	Small	7	25.93
	Not at all	11	40.74
	Don't know	2	7.41
	Great	4	7.55
	Moderate	14	26.42
70+	Small	15	28.30
	Not at all	15	28.30
	Don't know	5	9.43

Extent mental health needs met by diagnosed with multiple neurological conditions.
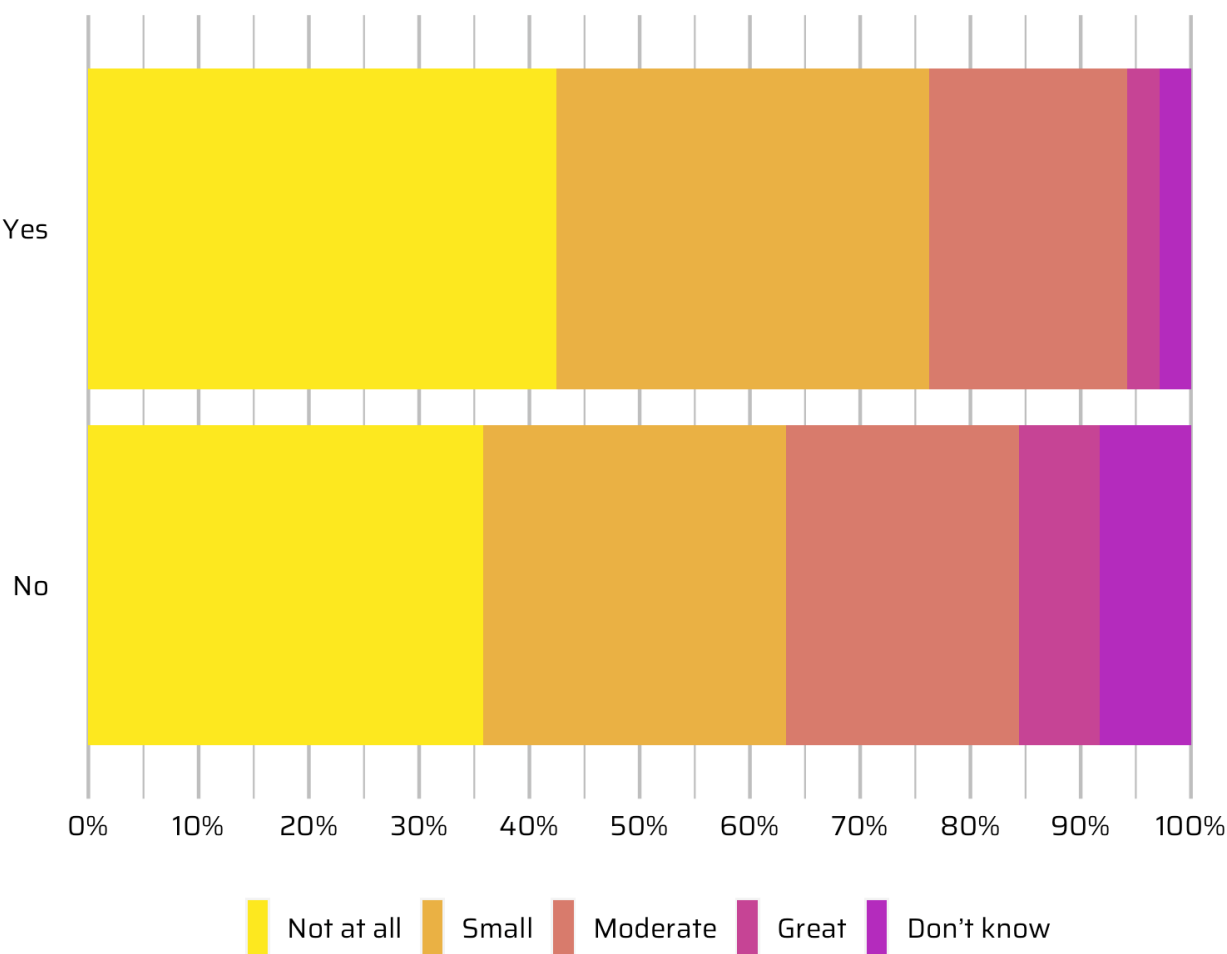
Figure 15: Extent respondents reported their mental health needs were being met, broken down by them being diagnosed with multiple neurological conditions.

Table 14: Extent respondents reported their mental health needs were being met, broken down by them being diagnosed with multiple neurological conditions.

Multiple	Extent	Respondents	Percentage
	Great	4	2.88
	Moderate	25	17.99
Yes	Small	47	33.81
	Not at all	59	42.45
	Don't know	4	2.88
	Great	8	7.34
No	Moderate	23	21.10

Multiple	Extent	Respondents	Percentage
	Small	30	27.52
	Not at all	39	35.78
	Don't know	9	8.26

Frequency NHS A&E/Emergency services were sought.
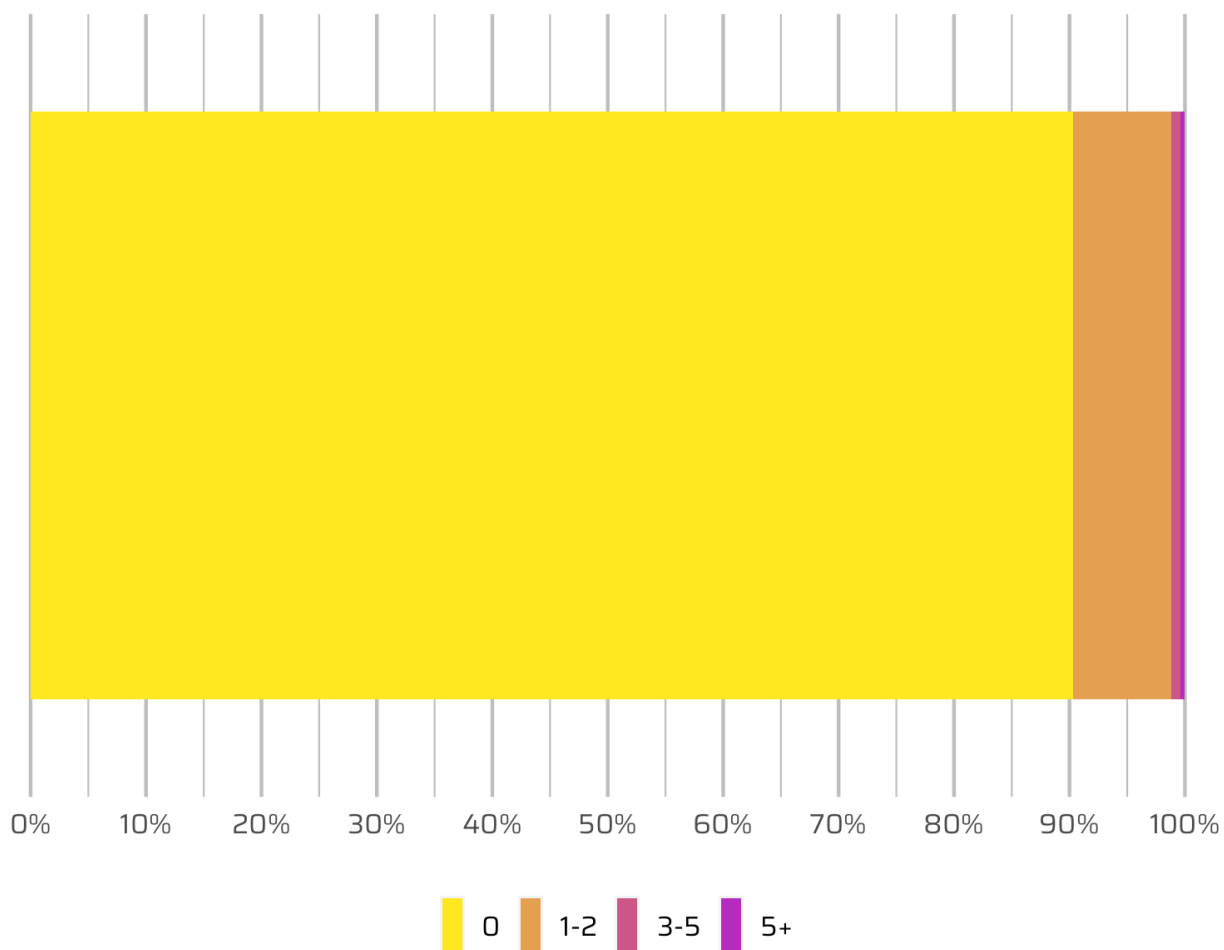
Figure 16: Frequency that NHS A&E or emergencies services were sort in the last 8 weeks.

Table 15: Frequency that NHS A&E or emergencies services were sort in the last 8 weeks.

Frequency	Respondents	Percentage
5+	1	0.40
3-5	2	0.81
1-2	21	8.47
0	224	90.32

Frequency NHS A&E/emergency support sought by gender

Figure 17: Frequency that NHS A&E or emergencies services were sort in the last 8 weeks broken down by gender of respondents.

Table 16: Frequency that NHS A&E or emergencies services were sort in the last 8 weeks broken down by gender of respondents.

Gender	Frequency	Respondents	Percentage
Female	5+	1	0.56
	3-5	1	0.56
	1-2	12	6.70
	0	165	92.18
Male	5+	0	0.00
	3-5	0	0.00
	1-2	9	13.43
	0	58	86.57

Gender	Frequency	Respondents	Percentage
Prefer not to say	5+	0	NaN
	3-5	0	NaN
	1-2	0	NaN
	0	0	NaN
Prefer to self-describe	5+	0	0.00
	3-5	1	50.00
	1-2	0	0.00
	0	1	50.00

Frequency NHS A&E/emergency support soughtby employment status.

Figure 17: Frequency that NHS A&E or emergencies services were sort in the last 8 weeks broken down by employment status.

Table 16: Frequency that NHS A&E or emergencies services were sort in the last 8 weeks broken down by employment status.

Employment status	Frequency	Respondents	Percentage
Employed (full time)	5+	0	0.00
	3-5	0	0.00
	1-2	1	4.17
	0	23	95.83
Employed (part time)	5+	0	0.00
	3-5	0	0.00
	1-2	2	11.76
	0	15	88.24
Homemaker	5+	0	0.00
	3-5	0	0.00
	1-2	1	16.67
	0	5	83.33
Other	5+	0	0.00
	3-5	0	0.00
	1-2	2	40.00
	0	3	60.00
Out of work	5+	0	0.00
	3-5	1	14.29
	1-2	1	14.29
	0	5	71.43
Prefer not to say	5+	0	NaN
	3-5	0	NaN
	1-2	0	NaN
	0	0	NaN
Retired	5+	1	1.16
	3-5	1	1.16
	1-2	3	3.49
	0	81	94.19
Self-employed (full time)	5+	0	0.00
	3-5	0	0.00
	1-2	1	20.00
	0	4	80.00
Self-employed (part time)	5+	0	0.00
	3-5	0	0.00

Employment status	Frequency	Respondents	Percentage
	1-2	0	0.00
	0	10	100.00
	5+	0	NaN
	3-5	0	NaN
	1-2	0	NaN
Student	0	0	NaN
	5+	0	0.00
	3-5	0	0.00
Unable to work	1-2	10	11.36
	0	78	88.64

Frequency NHS A&E/emergency support sought by number of dependents
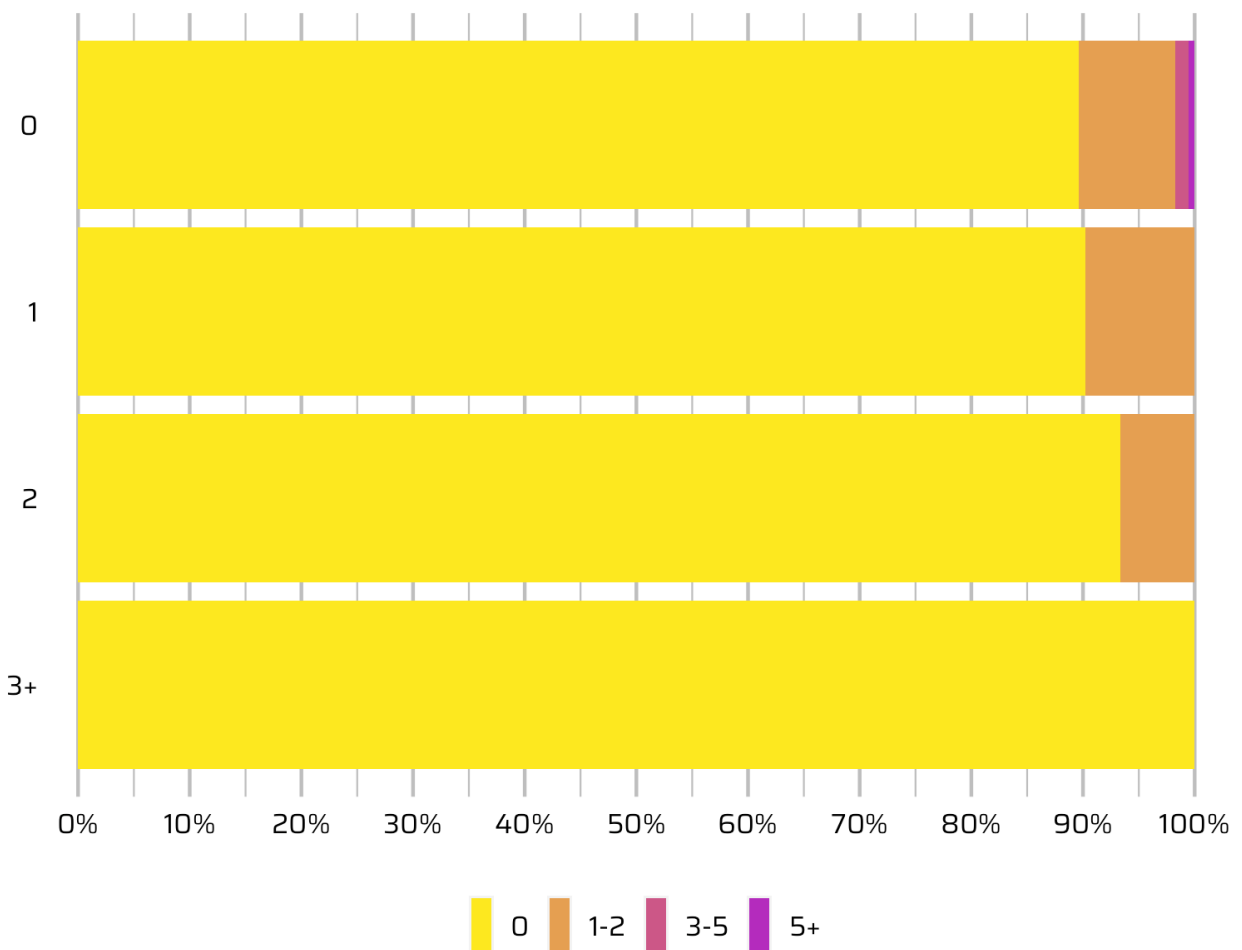
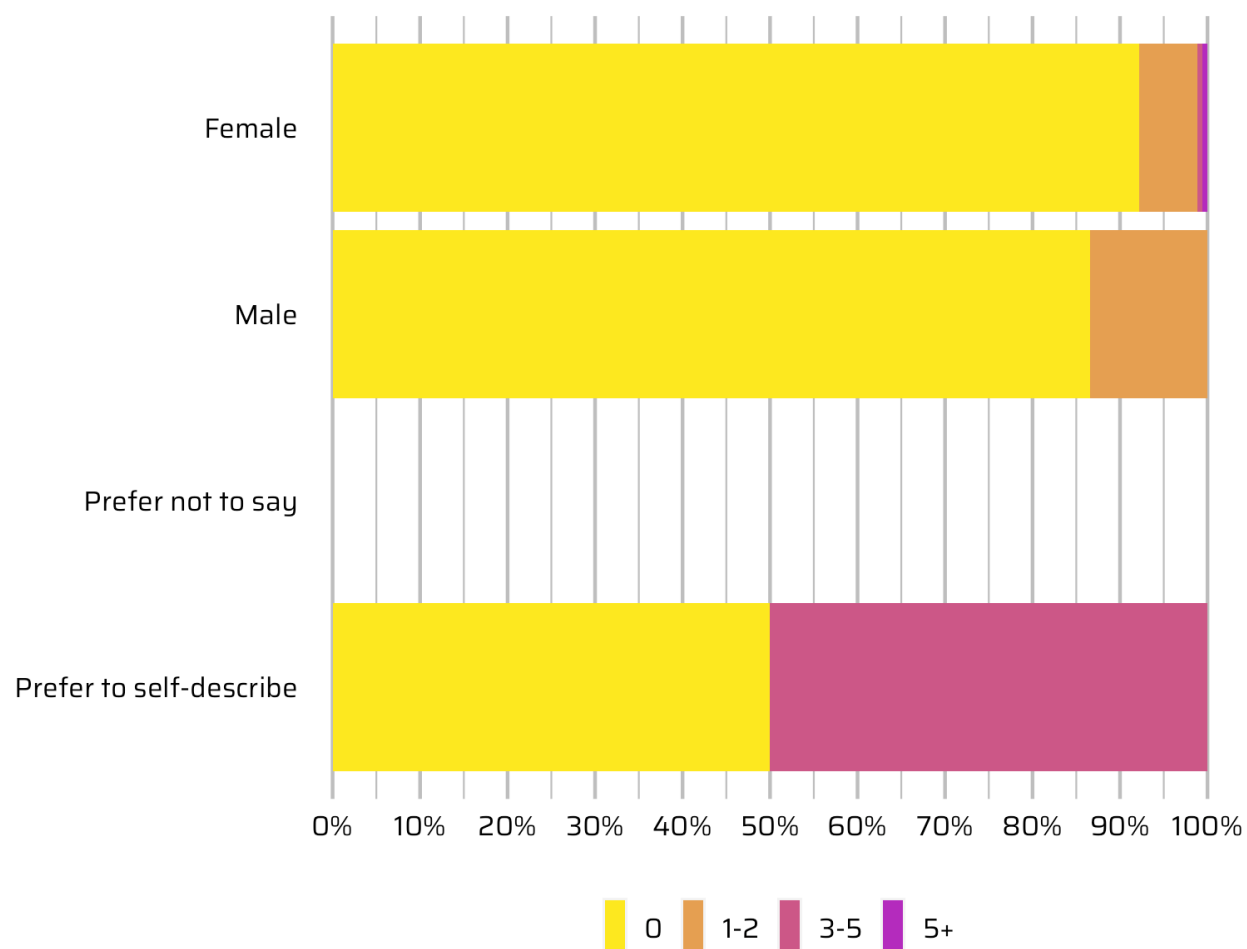*Figure 18: Frequency that NHS A&E or emergencies services were sort in the last 8 weeks broken down by number of dependents.*

Table 17: Frequency that NHS A&E or emergencies services were sort in the last 8 weeks broken down by number of dependents.

Dependents	Frequency	Respondents	Percentage
0	5+	1	0.57
	3-5	2	1.15
	1-2	15	8.62
	0	156	89.66
1	5+	0	0.00
	3-5	0	0.00
	1-2	5	9.80
	0	46	90.20
2	5+	0	0.00
	3-5	0	0.00
	1-2	1	6.67
	0	14	93.33
3+	5+	0	0.00
	3-5	0	0.00
	1-2	0	0.00
	0	8	100.00

Frequency NHS A&E/emergency support sought by feeling axious or hopeless
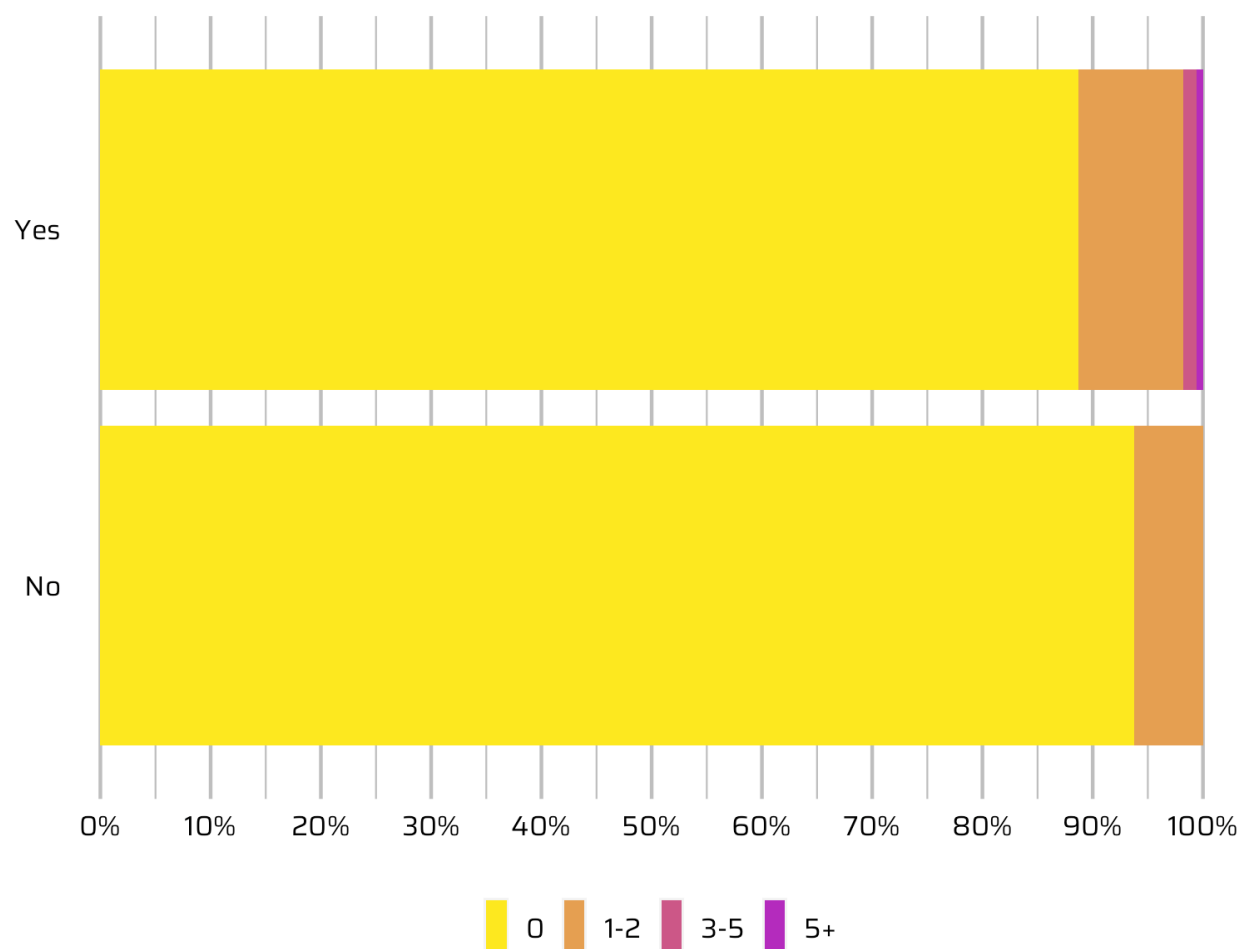
Figure 19: Frequency that NHS A&E or emergencies services were sort in the last 8 weeks broken down by reporting feeling anxious or hopeless.

Table 18: Frequency that NHS A&E or emergencies services were sort in the last 8 weeks broken down by reporting feeling anxious or hopeless.

Anxious or hopeless	Frequency	Respondents	Percentage
	5+	1	0.60
	3-5	2	1.19
Yes	1-2	16	9.52
	0	149	88.69
	5+	0	0.00
	3-5	0	0.00
No	1-2	5	6.25
	0	75	93.75

Frequency NHS A&E/emergency support sought by age

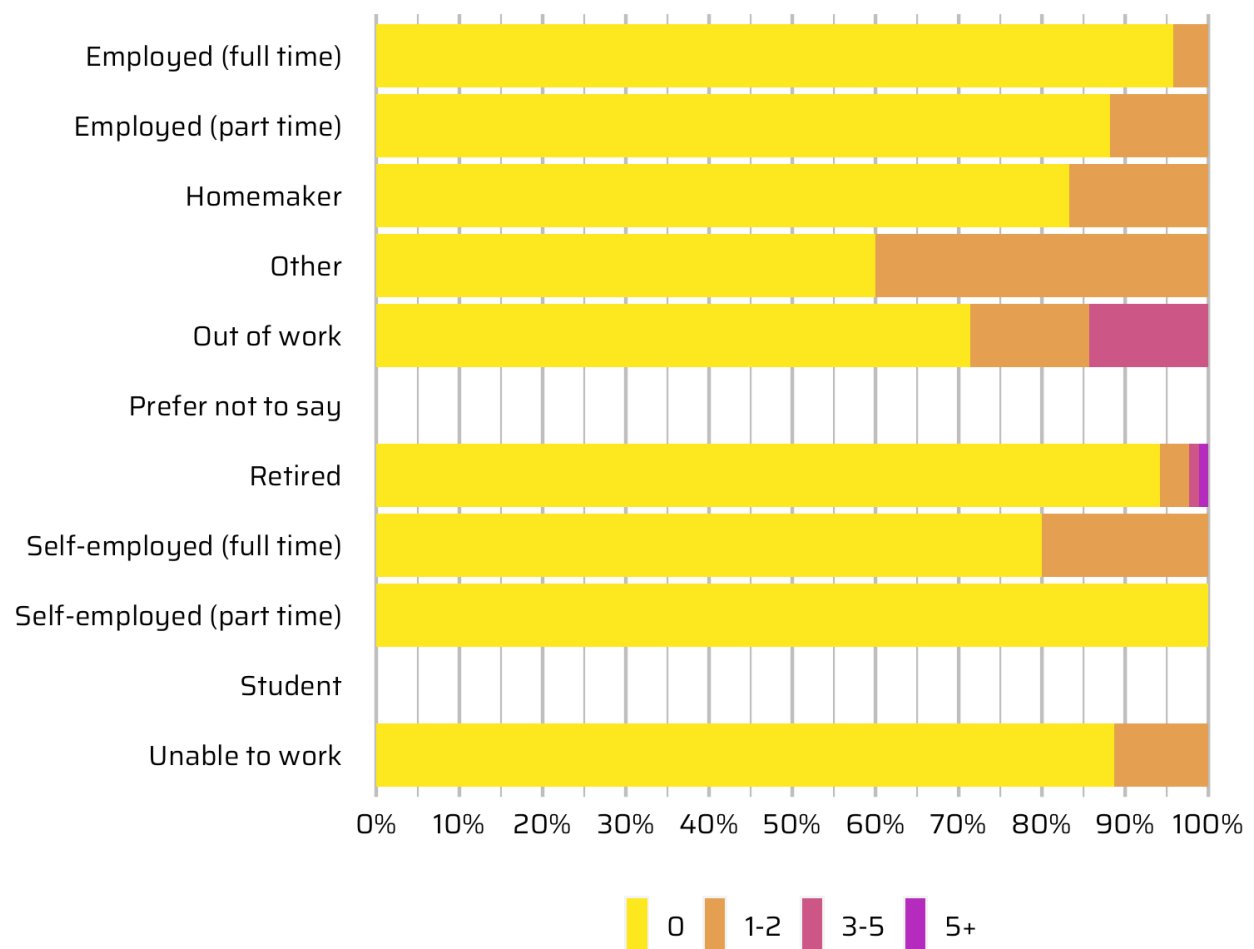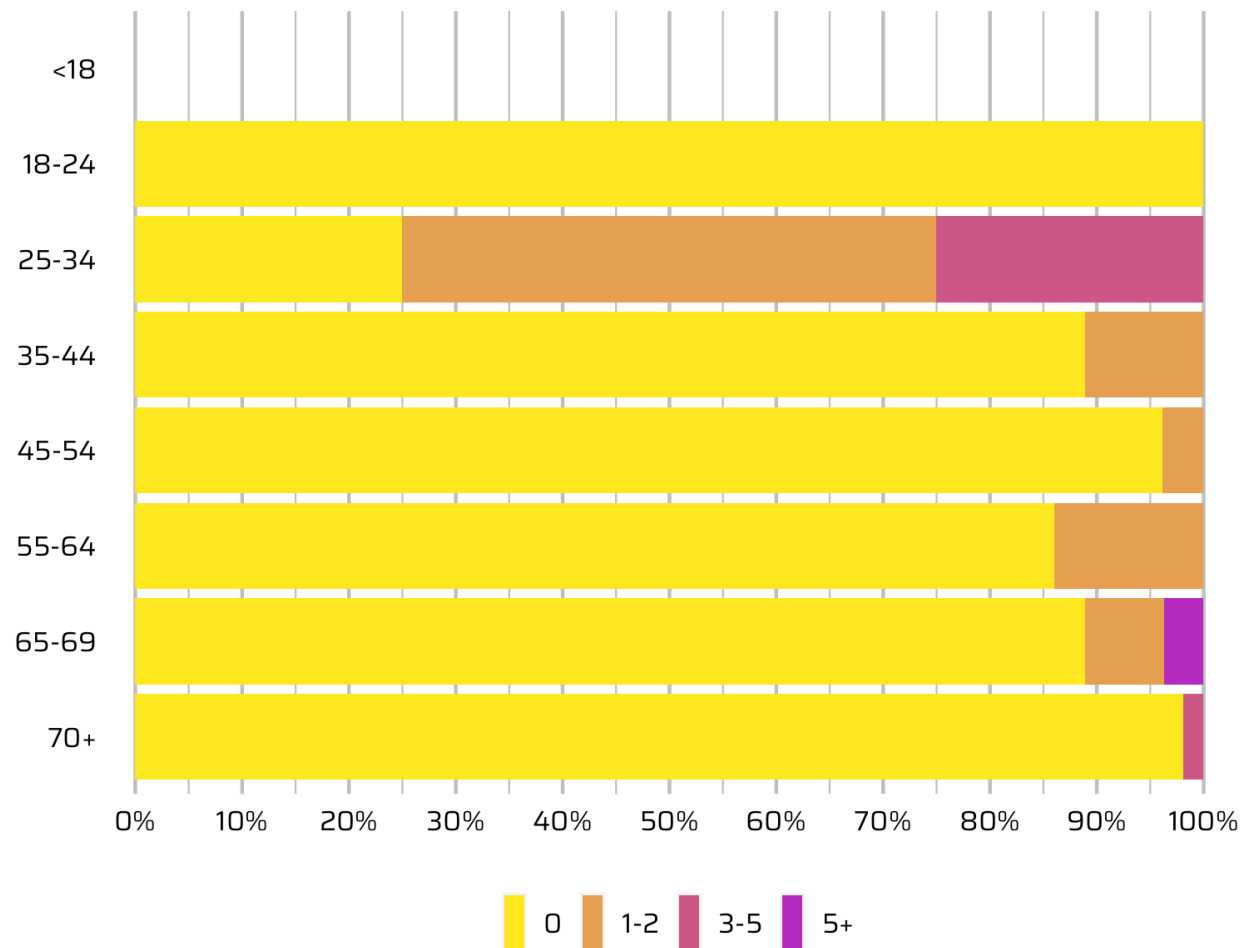*Figure 20: Frequency that NHS A&E or emergencies services were sort in the last 8 weeks broken down by age.*

Table 19: Frequency that NHS A&E or emergencies services were sort in the last 8 weeks broken down by age.

Age	Frequency	Respondents	Percentage
<18	5+	0	NaN
	3-5	0	NaN
	1-2	0	NaN
	0	0	NaN
18-24	5+	0	0.00
	3-5	0	0.00
	1-2	0	0.00
	0	1	100.00

Age	Frequency	Respondents	Percentage
	5+	0	0.00
25-34	3-5	1	25.00
	1-2	2	50.00
	0	1	25.00
	5+	0	0.00
35-44	3-5	0	0.00
	1-2	2	11.11
	0	16	88.89
	5+	0	0.00
45-54	3-5	0	0.00
	1-2	2	3.85
	0	50	96.15
	5+	0	0.00
55-64	3-5	0	0.00
	1-2	13	13.98
	0	80	86.02
	5+	1	3.70
65-69	3-5	0	0.00
	1-2	2	7.41
	0	24	88.89
	5+	0	0.00
70+	3-5	1	1.89
	1-2	0	0.00
	0	52	98.11

Frequency NHS A&E/emergency support sought by multiple neurological conditions
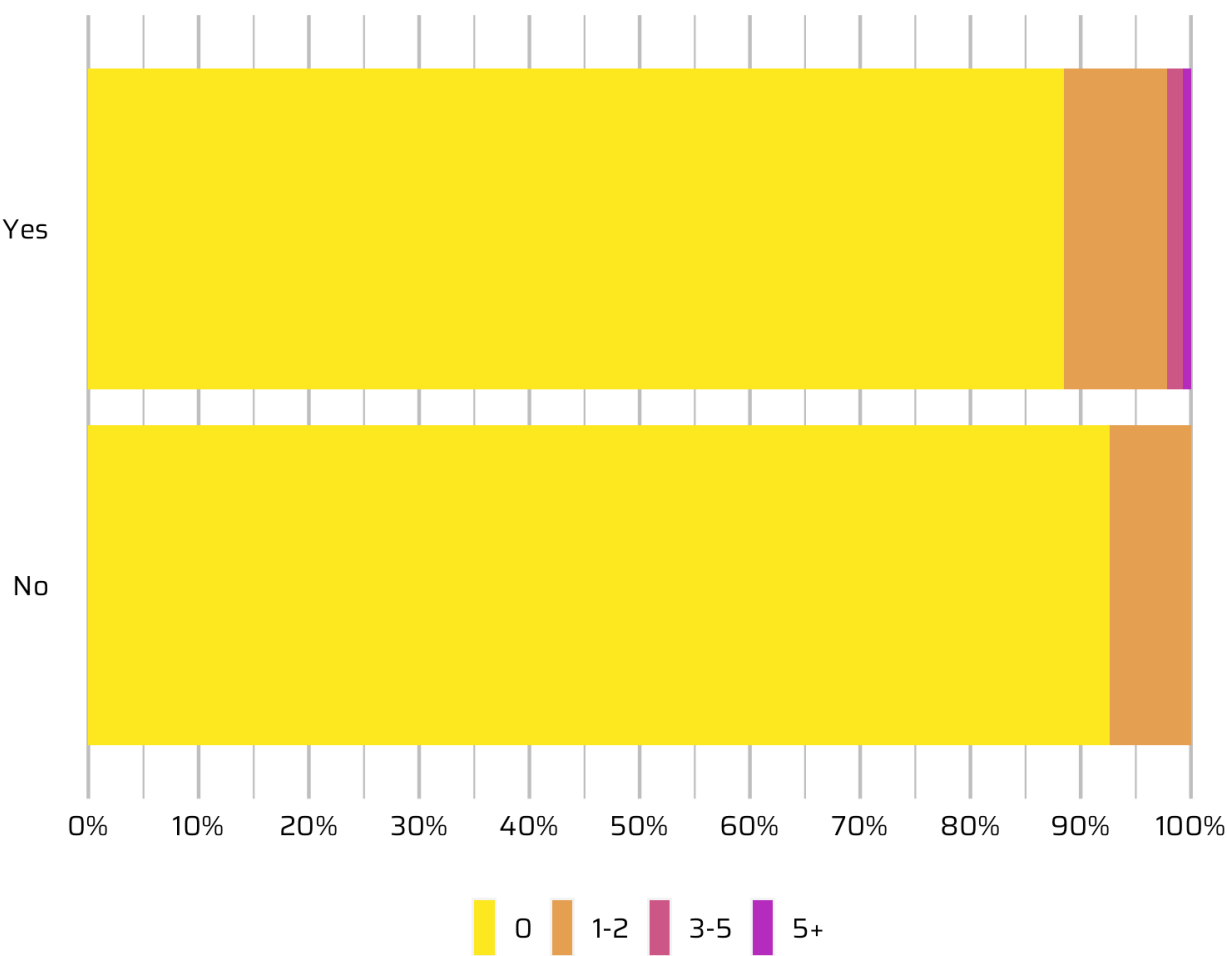
Figure 21: Frequency that NHS A&E or emergencies services were sort in the last 8 weeks broken down by being diagnosed with multiple conditions.

Table 20: Frequency that NHS A&E or emergencies services were sort in the last 8 weeks broken down by being diagnosed with multiple conditions.

Multiple	Frequency	Respondents	Percentage
	5+	1	0.72
Yes	3-5	2	1.44
	1-2	13	9.35
	0	123	88.49
	5+	0	0.00
No	3-5	0	0.00
	1-2	8	7.34

Multiple	Frequency	Respondents	Percentage
	0	101	92.66

Experience of healthcare overall
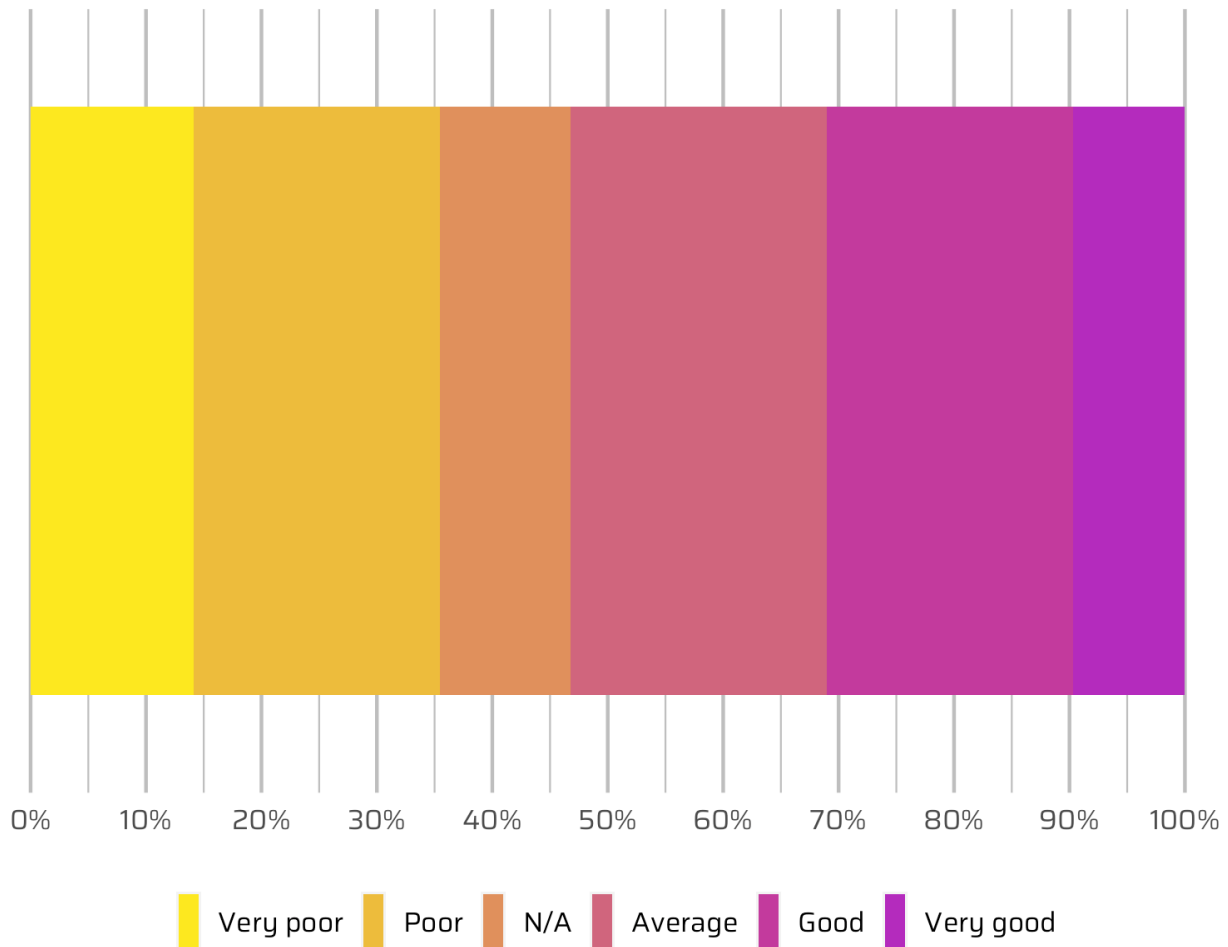
Figure 22: Respondents overall experience of healthcare.

Table 21: Respondents overall experience of healthcare.

Experience	Respondents	Percentage
Very good	24	9.68
Good	53	21.37
Average	55	22.18
N/A	28	11.29
Poor	53	21.37
Very poor	35	14.11

Overall experience of healthcare by gender
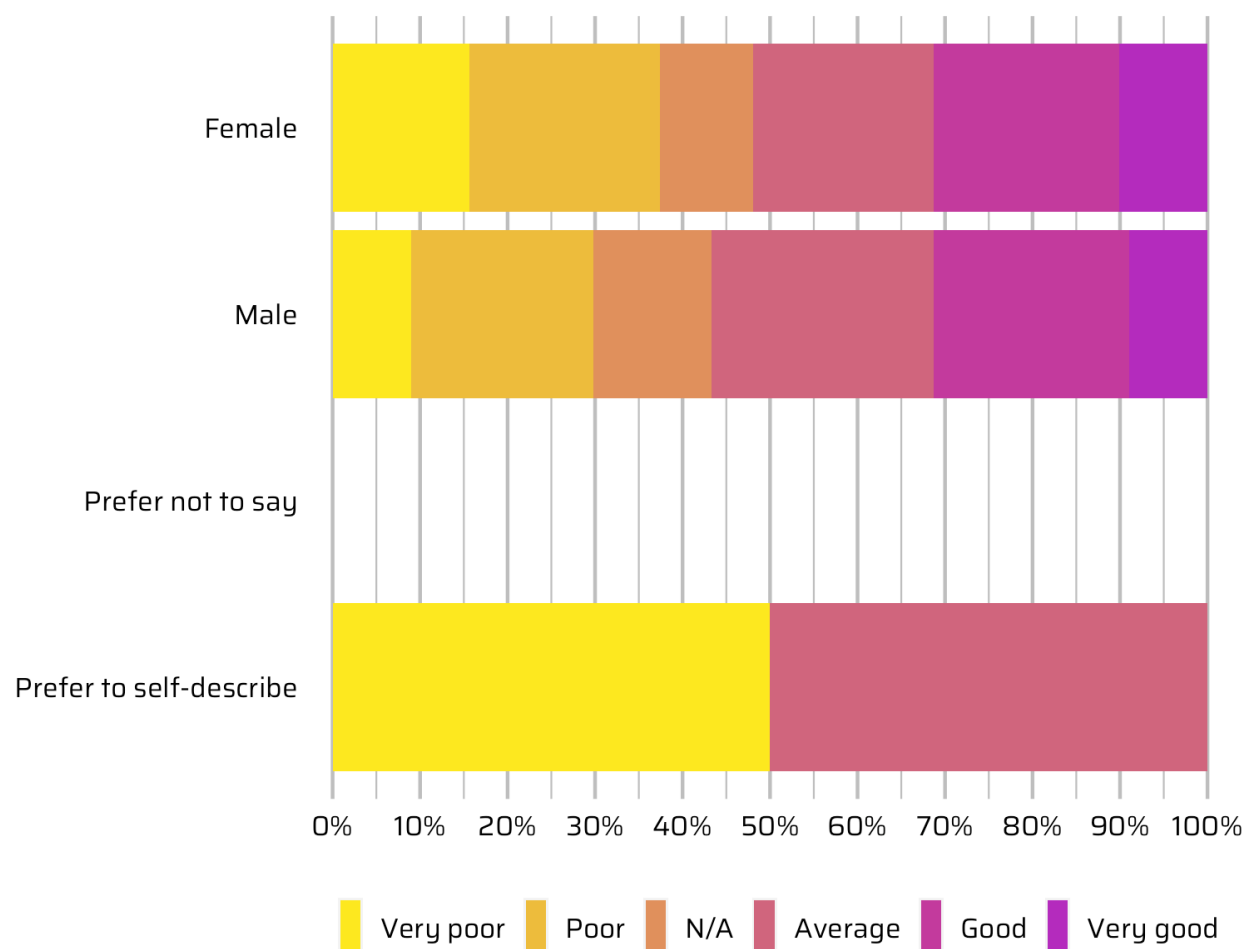
Figure 23: Respondents overall experience of healthcare broken down by gender.

Table 22: Respondents overall experience of healthcare broken down by gender.

Gender	Experience	Respondents	Percentage
	Very good	18	10.06
	Good	38	21.23
	Average	37	20.67
Female	N/A	19	10.61
	Poor	39	21.79
	Very poor	28	15.64
	Very good	6	8.96
	Good	15	22.39
Male	Average	17	25.37
	N/A	9	13.43

Gender	Experience	Respondents	Percentage
	Poor	14	20.90
	Very poor	6	8.96
	Very good	0	NaN
	Good	0	NaN
Prefer not to say	Average	0	NaN
	N/A	0	NaN
	Poor	0	NaN
	Very poor	0	NaN
	Very good	0	0.00
	Good	0	0.00
Prefer to self-describe	Average	1	50.00
	N/A	0	0.00
	Poor	0	0.00
	Very poor	1	50.00

Overall experience of healthcare by employment status

Figure 24: Respondents overall experience of healthcare broken down by employment status.

Table 23: Respondents overall experience of healthcare broken down by employment status.

Employment status	Experience	Respondents	Percentage
	Very good	0	0.00
	Good	4	16.67
	Average	7	29.17
Employed (full time)	N/A	6	25.00
	Poor	6	25.00
	Very poor	1	4.17
	Very good	1	5.88
	Good	3	17.65
Employed (part time)	Average	3	17.65
	N/A	1	5.88

Employment status	Experience	Respondents	Percentage
	Poor	5	29.41
	Very poor	4	23.53
	Very good	1	16.67
	Good	1	16.67
Homemaker	Average	1	16.67
	N/A	1	16.67
	Poor	0	0.00
	Very poor	2	33.33
	Very good	0	0.00
	Good	2	40.00
Other	Average	2	40.00
	N/A	1	20.00
	Poor	0	0.00
	Very poor	0	0.00
	Very good	0	0.00
	Good	2	28.57
Out of work	Average	3	42.86
	N/A	0	0.00
	Poor	1	14.29
	Very poor	1	14.29
	Very good	0	NaN
	Good	0	NaN
Prefer not to say	Average	0	NaN
	N/A	0	NaN
	Poor	0	NaN
	Very poor	0	NaN
	Very good	10	11.63
	Good	22	25.58
Retired	Average	19	22.09
	N/A	4	4.65
	Poor	20	23.26
	Very poor	11	12.79
	Very good	1	20.00
	Good	0	0.00
Self-employed (full time)	Average	0	0.00
	N/A	0	0.00

Employment status	Experience	Respondents	Percentage
Self-employed (part time)	Poor	4	80.00
	Very poor	0	0.00
	Very good	0	0.00
	Good	6	60.00
	Average	0	0.00
	N/A	1	10.00
Student	Poor	3	30.00
	Very poor	0	0.00
	Very good	0	NaN
	Good	0	NaN
	Average	0	NaN
	N/A	0	NaN
	Poor	0	NaN
	Very poor	0	NaN
Unable to work	Very good	11	12.50
	Good	13	14.77
	Average	20	22.73
	N/A	14	15.91
	Poor	14	15.91
	Very poor	16	18.18

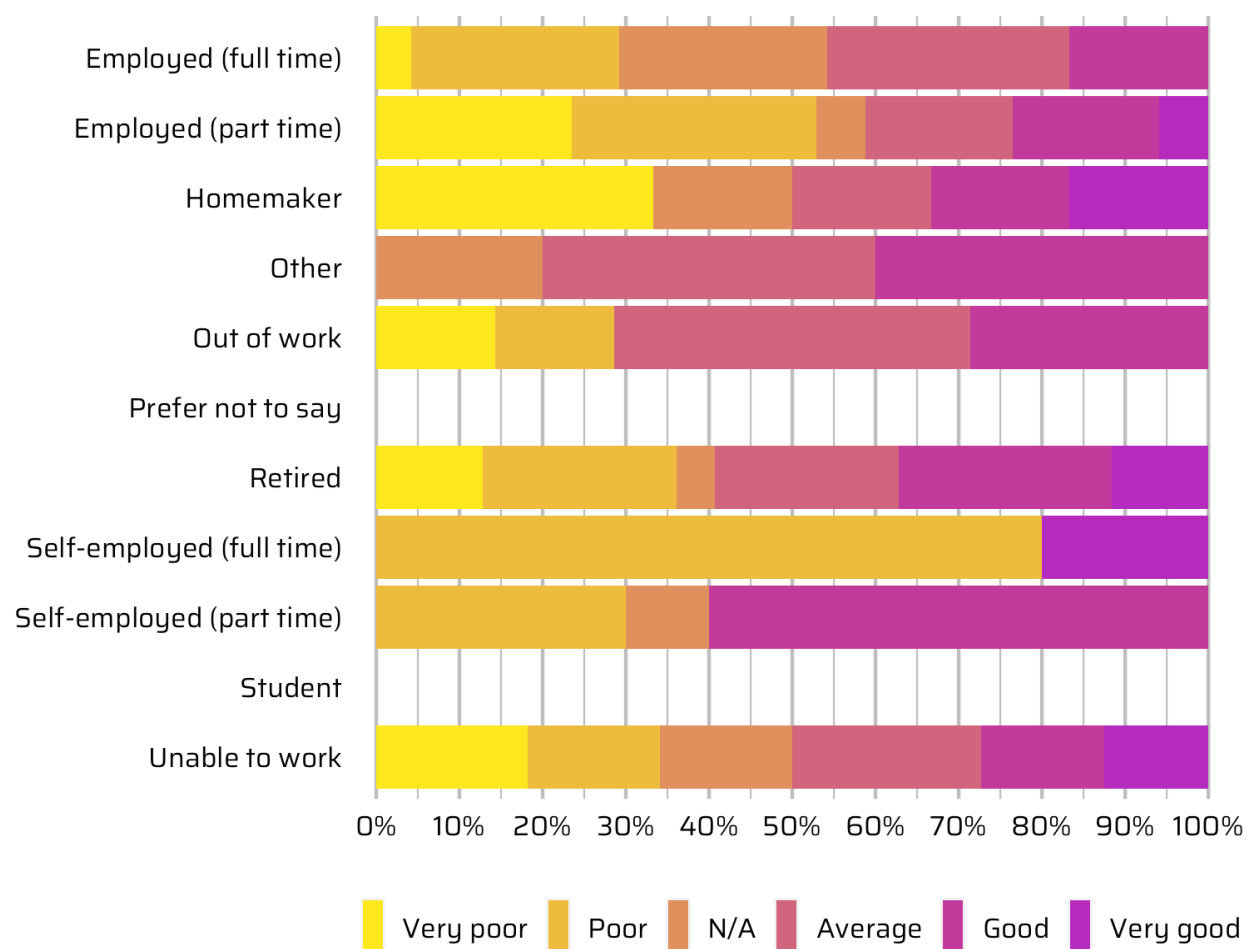## Overall experience of healthcare by number of dependents

Figure 25: Respondents overall experience of healthcare broken down by number of dependents.

Table 24: Respondents overall experience of healthcare broken down by number of dependents.

Dependents	Experience	Respondents	Percentage
0	Very good	23	13.22
	Good	40	22.99
	Average	34	19.54
	N/A	15	8.62
	Poor	37	21.26
	Very poor	25	14.37
1	Very good	1	1.96
	Good	11	21.57
	Average	12	23.53
	N/A	8	15.69

Dependents	Experience	Respondents	Percentage
	Poor	10	19.61
	Very poor	9	17.65
	Very good	0	0.00
	Good	1	6.67
2	Average	6	40.00
	N/A	4	26.67
	Poor	4	26.67
	Very poor	0	0.00
	Very good	0	0.00
	Good	1	12.50
3+	Average	3	37.50
	N/A	1	12.50
	Poor	2	25.00
	Very poor	1	12.50

Overall experience of healthcare by feeling anxious or hopeless
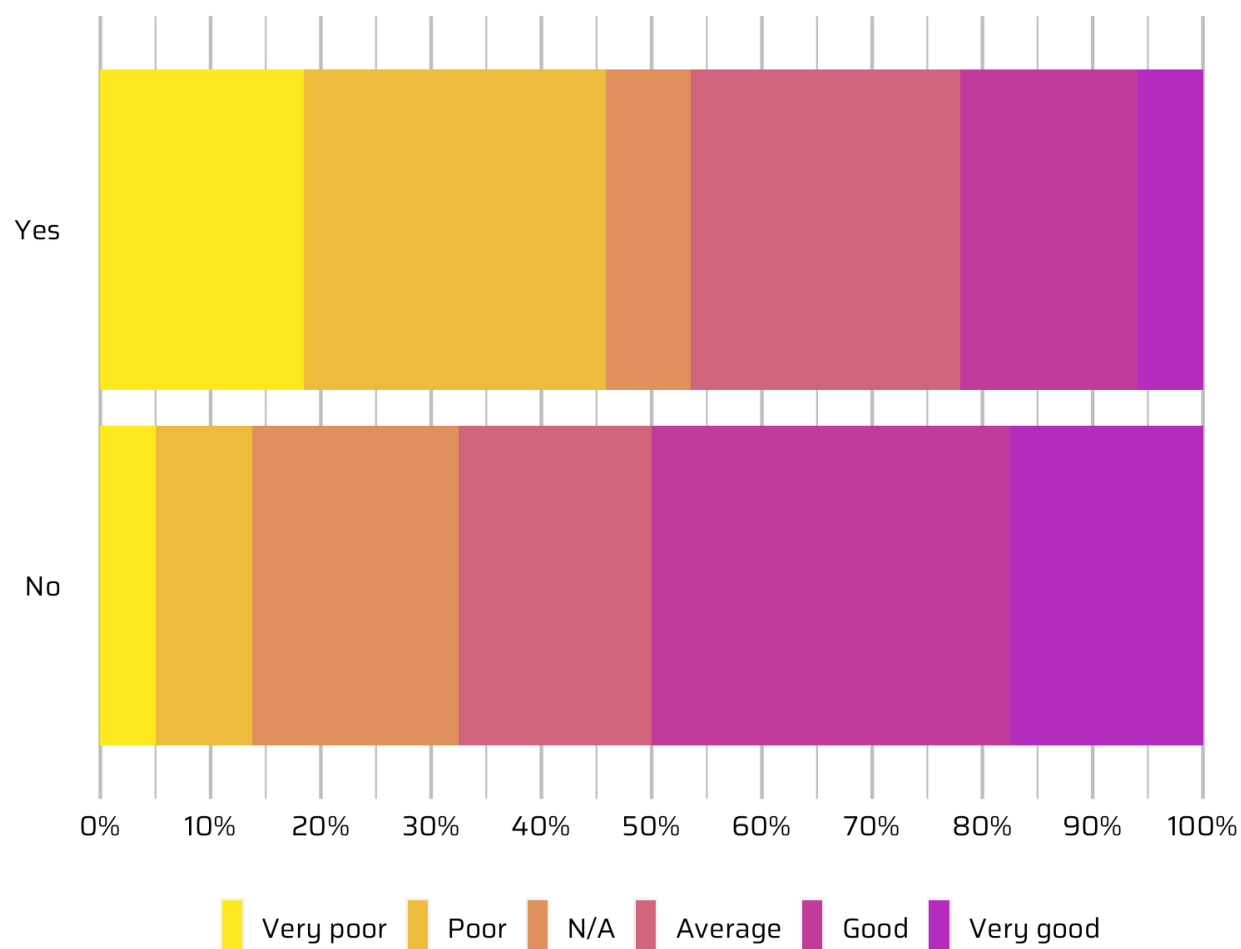
Figure 26: Respondents overall experience of healthcare broken down by reporting feeling anxious or hopeless.

Table 25: Respondents overall experience of healthcare broken down by reporting feeling anxious or hopeless.

Anxious or hopeless	Experience	Respondents	Percentage
	Very good	10	5.95
	Good	27	16.07
	Average	41	24.40
Yes	N/A	13	7.74
	Poor	46	27.38
	Very poor	31	18.45
No	Very good	14	17.50
	Good	26	32.50

Anxious or hopeless	Experience	Respondents	Percentage
	Average	14	17.50
	N/A	15	18.75
	Poor	7	8.75
	Very poor	4	5.00

Overall experience of healthcare by age.

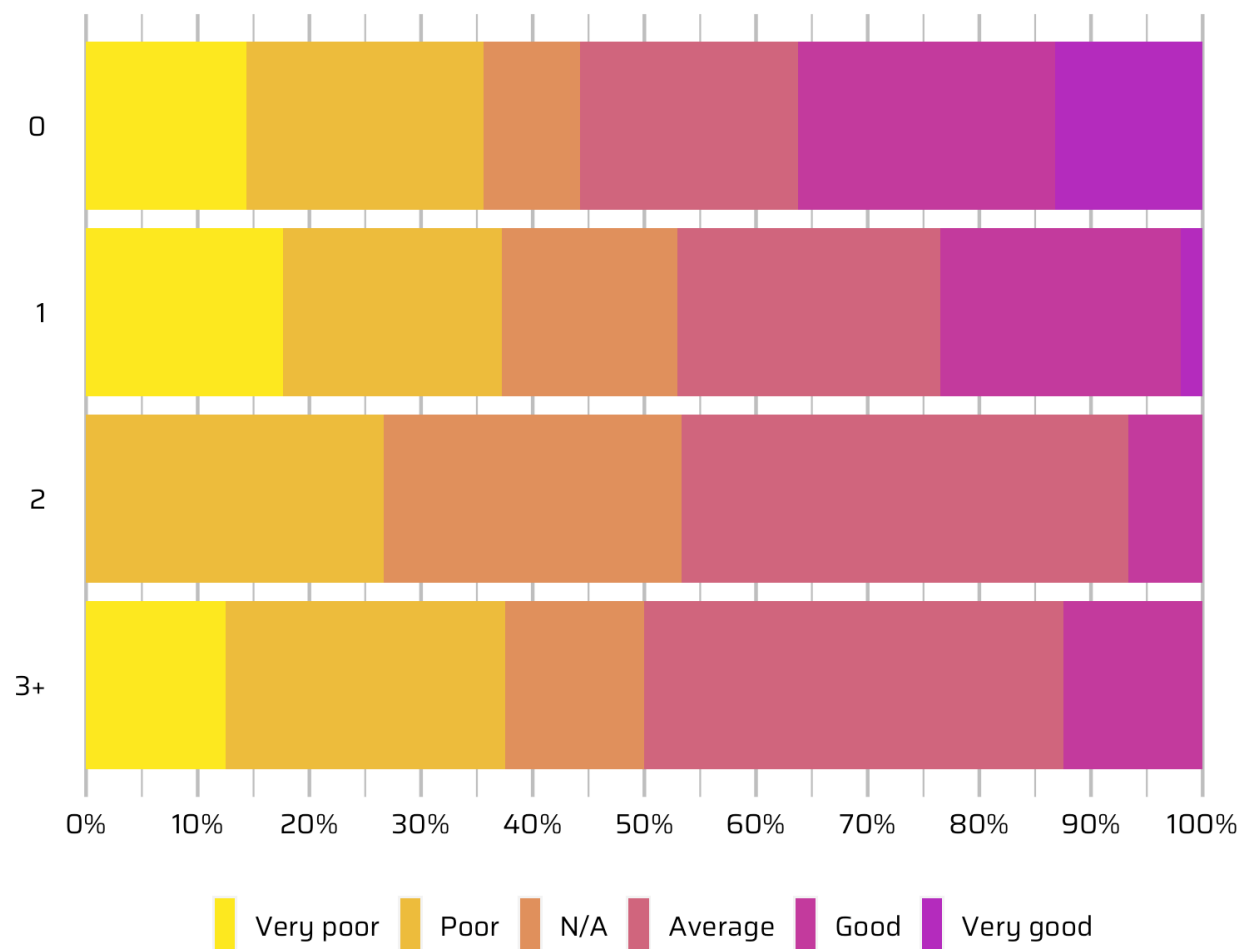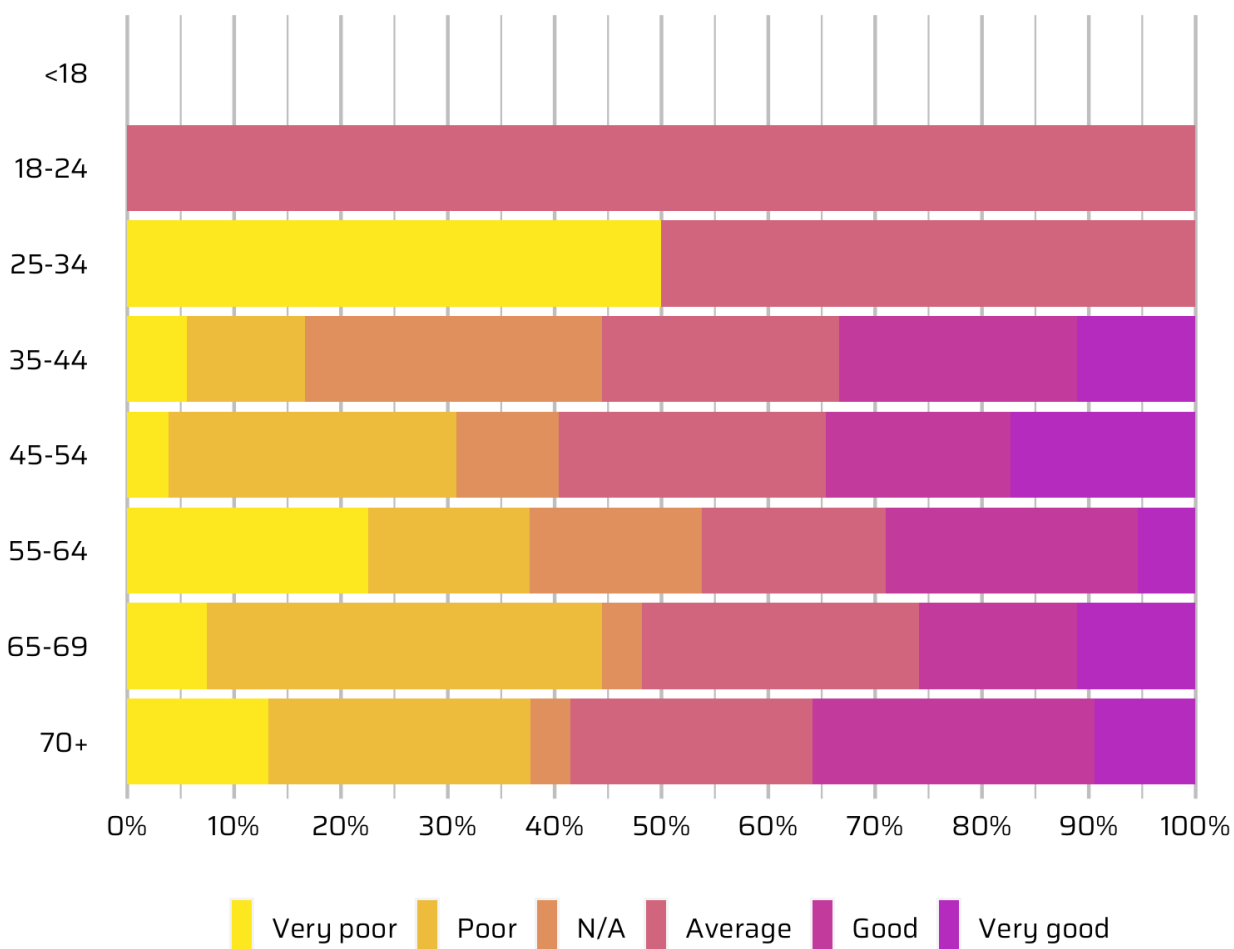*Figure 27: Respondents overall experience of healthcare broken down by age.*

Table 26: Respondents overall experience of healthcare broken down by age.

Age	Experience	Respondents	Percentage
	Very good	0	NaN
<18	Good	0	NaN
	Average	0	NaN

Age	Experience	Respondents	Percentage
	N/A	0	NaN
	Poor	0	NaN
	Very poor	0	NaN
	Very good	0	0.00
	Good	0	0.00
18-24	Average	1	100.00
	N/A	0	0.00
	Poor	0	0.00
	Very poor	0	0.00
	Very good	0	0.00
	Good	0	0.00
25-34	Average	2	50.00
	N/A	0	0.00
	Poor	0	0.00
	Very poor	2	50.00
	Very good	2	11.11
	Good	4	22.22
35-44	Average	4	22.22
	N/A	5	27.78
	Poor	2	11.11
	Very poor	1	5.56
	Very good	9	17.31
	Good	9	17.31
45-54	Average	13	25.00
	N/A	5	9.62
	Poor	14	26.92
	Very poor	2	3.85
	Very good	5	5.38
	Good	22	23.66
55-64	Average	16	17.20
	N/A	15	16.13
	Poor	14	15.05
	Very poor	21	22.58
	Very good	3	11.11
65-69	Good	4	14.81
	Average	7	25.93

Age	Experience	Respondents	Percentage
	N/A	1	3.70
	Poor	10	37.04
	Very poor	2	7.41
	Very good	5	9.43
	Good	14	26.42
70+	Average	12	22.64
	N/A	2	3.77
	Poor	13	24.53
	Very poor	7	13.21

Overall experience of healthcare by multiple neurological conditions.
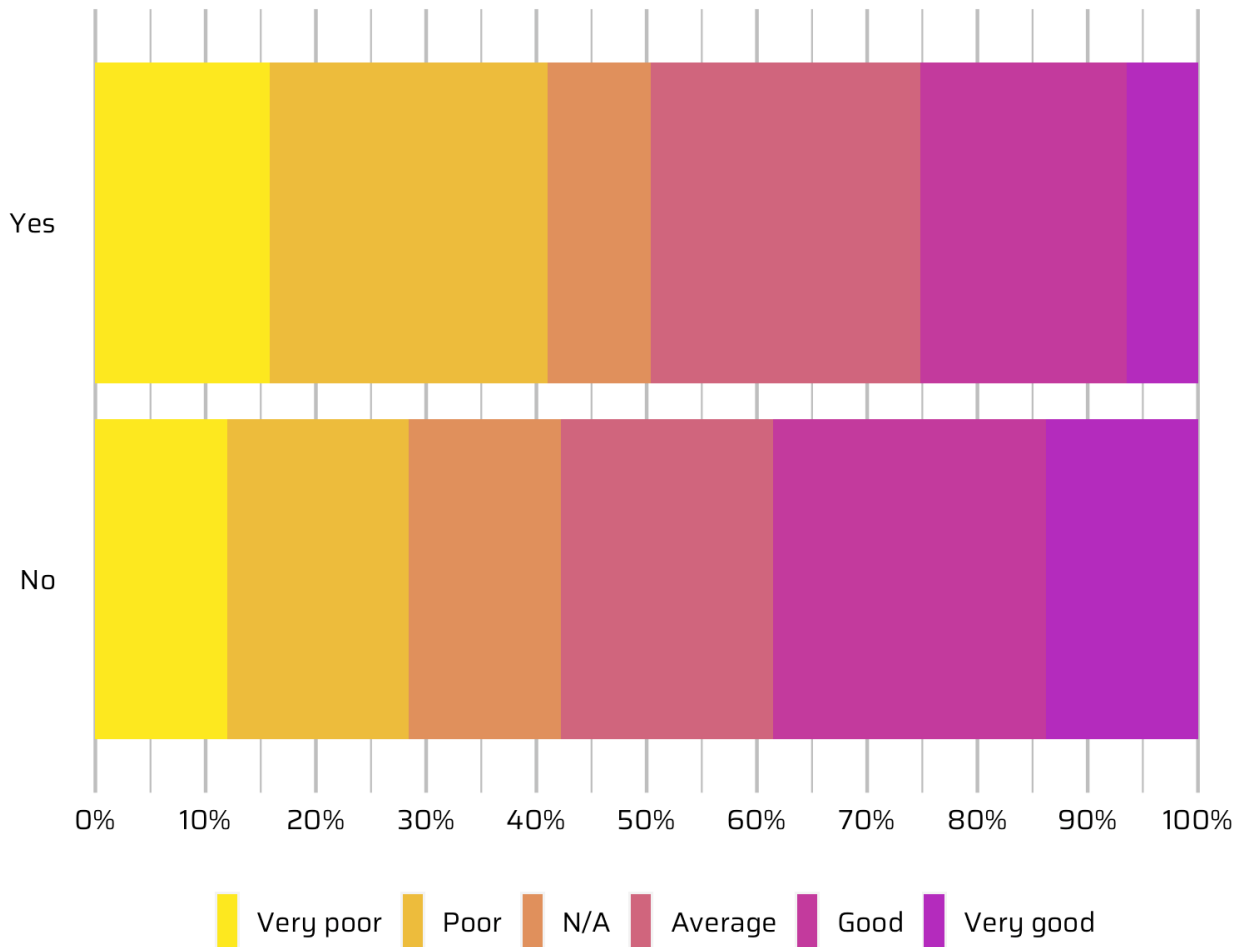
Figure 28: Respondents overall experience of healthcare broken down by if they were diagnosed with multiple neurological conditions.

Table 27: Respondents overall experience of healthcare broken down by if they were diagnosed with multiple neurological conditions.

Multiple	Experience	Respondents	Percentage
Yes	Very good	9	6.47
	Good	26	18.71
	Average	34	24.46
	N/A	13	9.35
	Poor	35	25.18
	Very poor	22	15.83
No	Very good	15	13.76
	Good	27	24.77
	Average	21	19.27
	N/A	15	13.76
	Poor	18	16.51
	Very poor	13	11.93

Demographics

Sample size

Total number of respondents: 248

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 139 respondents, equating to 56% of respondents, indicated that they have multiple (i.e., more than one) neurological conditions. In total, there are 72 conditions reported.
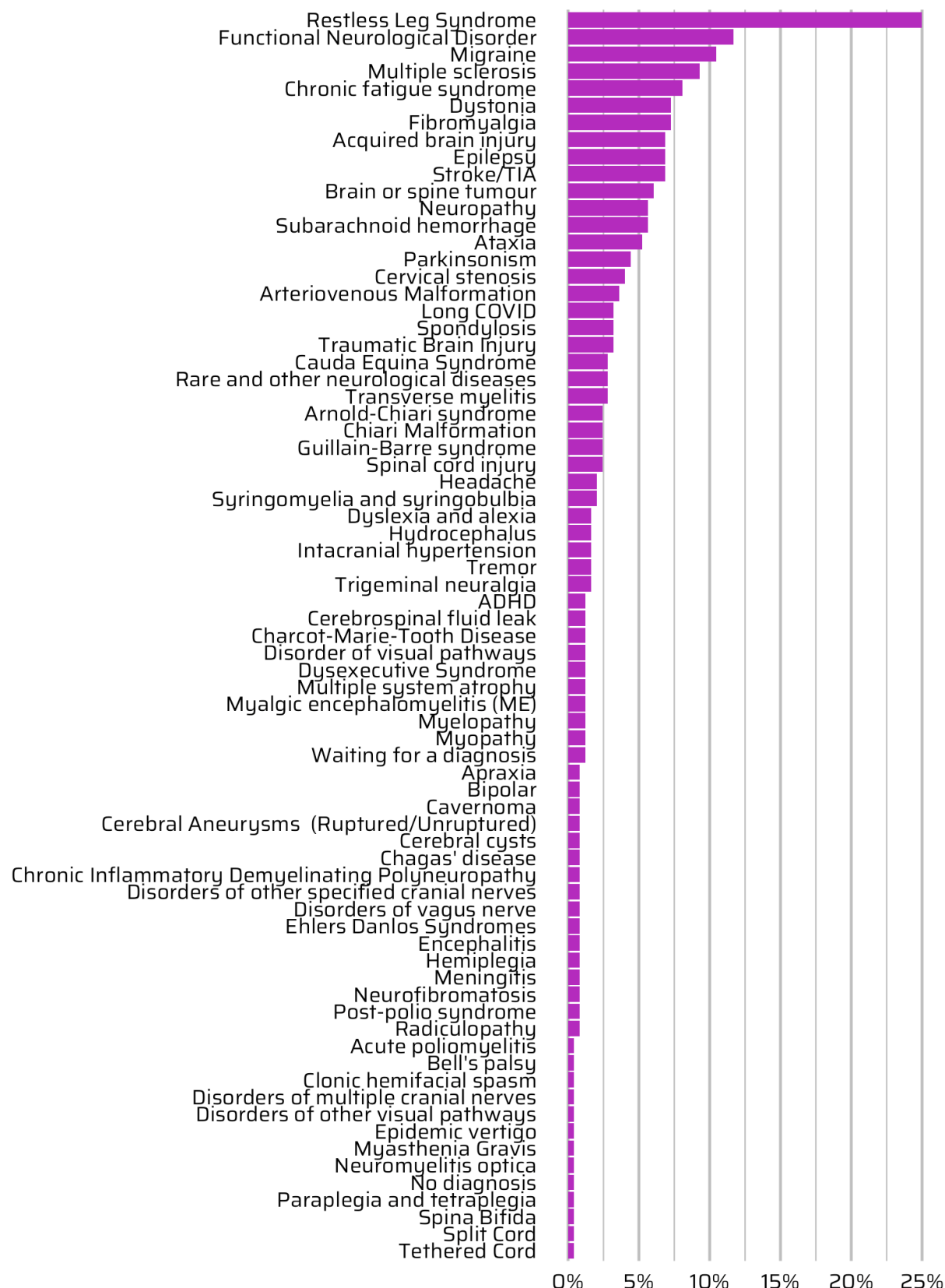
Figure 29: Neurological conditions respondents reported to be diagnosed with.

Table 28: Neurological conditions respondents reported to be diagnosed with.

Condition	Respondents	Percentage
Restless Leg Syndrome	62	25.00
Functional Neurological Disorder	29	11.69
Migraine	26	10.48
Multiple sclerosis	23	9.27
Chronic fatigue syndrome	20	8.06
Dystonia	18	7.26
Fibromyalgia	18	7.26
Acquired brain injury	17	6.85
Epilepsy	17	6.85
Stroke/TIA	17	6.85
Brain or spine tumour	15	6.05
Neuropathy	14	5.65
Subarachnoid hemorrhage	14	5.65
Ataxia	13	5.24
Parkinsonism	11	4.44
Cervical stenosis	10	4.03
Arteriovenous Malformation	9	3.63
Long COVID	8	3.23
Spondylosis	8	3.23
Traumatic Brain Injury	8	3.23
Cauda Equina Syndrome	7	2.82
Rare and other neurological diseases	7	2.82
Transverse myelitis	7	2.82
Arnold-Chiari syndrome	6	2.42
Chiari Malformation	6	2.42
Guillain-Barre syndrome	6	2.42
Spinal cord injury	6	2.42
Headache	5	2.02
Syringomyelia and syringobulbia	5	2.02
Dyslexia and alexia	4	1.61
Hydrocephalus	4	1.61
Intacranial hypertension	4	1.61
Tremor	4	1.61
Trigeminal neuralgia	4	1.61
ADHD	3	1.21

Condition	Respondents	Percentage
Cerebrospinal fluid leak	3	1.21
Charcot-Marie-Tooth Disease	3	1.21
Disorder of visual pathways	3	1.21
Dysexecutive Syndrome	3	1.21
Multiple system atrophy	3	1.21
Myalgic encephalomyelitis (ME)	3	1.21
Myelopathy	3	1.21
Myopathy	3	1.21
Waiting for a diagnosis	3	1.21
Apraxia	2	0.81
Bipolar	2	0.81
Cavernoma	2	0.81
Cerebral Aneurysms (Ruptured/Unruptured)	2	0.81
Cerebral cysts	2	0.81
Chagas' disease	2	0.81
Chronic Inflammatory Demyelinating Polyneuropathy	2	0.81
Disorders of other specified cranial nerves	2	0.81
Disorders of vagus nerve	2	0.81
Ehlers Danlos Syndromes	2	0.81
Encephalitis	2	0.81
Hemiplegia	2	0.81
Meningitis	2	0.81
Neurofibromatosis	2	0.81
Post-polio syndrome	2	0.81
Radiculopathy	2	0.81
Acute poliomyelitis	1	0.40
Bell's palsy	1	0.40
Clonic hemifacial spasm	1	0.40
Disorders of multiple cranial nerves	1	0.40
Disorders of other visual pathways	1	0.40
Epidemic vertigo	1	0.40
Myasthenia Gravis	1	0.40
Neuromyelitis optica	1	0.40
No diagnosis	1	0.40
Paraplegia and tetraplegia	1	0.40

Condition	Respondents	Percentage
Spina Bifida	1	0.40
Split Cord	1	0.40
Tethered Cord	1	0.40

Age at diagnosis
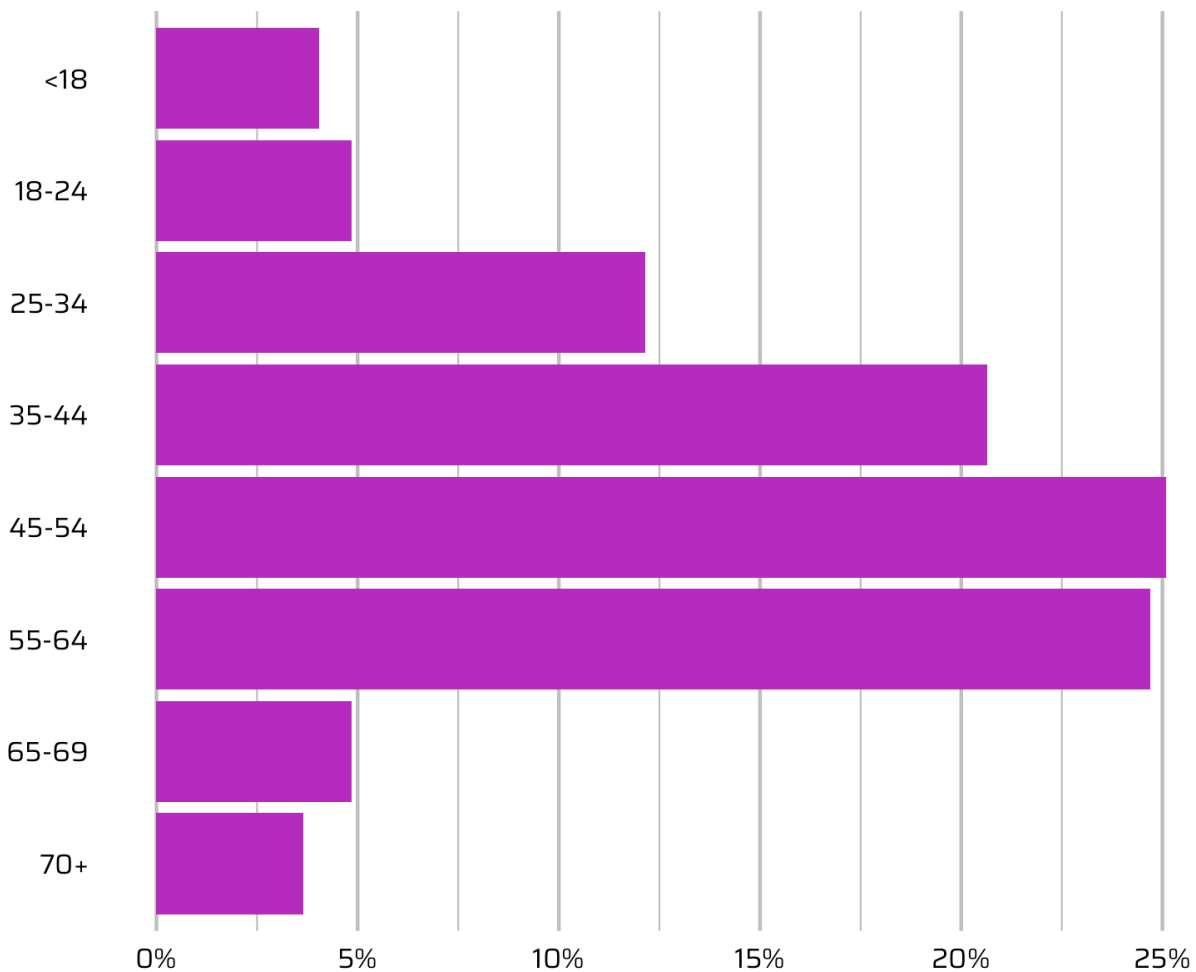
Figure 30: Age of respondents when they were first diagnosed with a Neurological condition.

Table 29: Age of respondents when they were first diagnosed with a Neurological condition.

Age when diagnosed	Respondents	Percentage
<18	10	4.05
18-24	12	4.86
25-34	30	12.15
35-44	51	20.65

Age when diagnosed	Respondents	Percentage
45-54	62	25.10
55-64	61	24.70
65-69	12	4.86
70+	9	3.64

Multiple neurological conditions
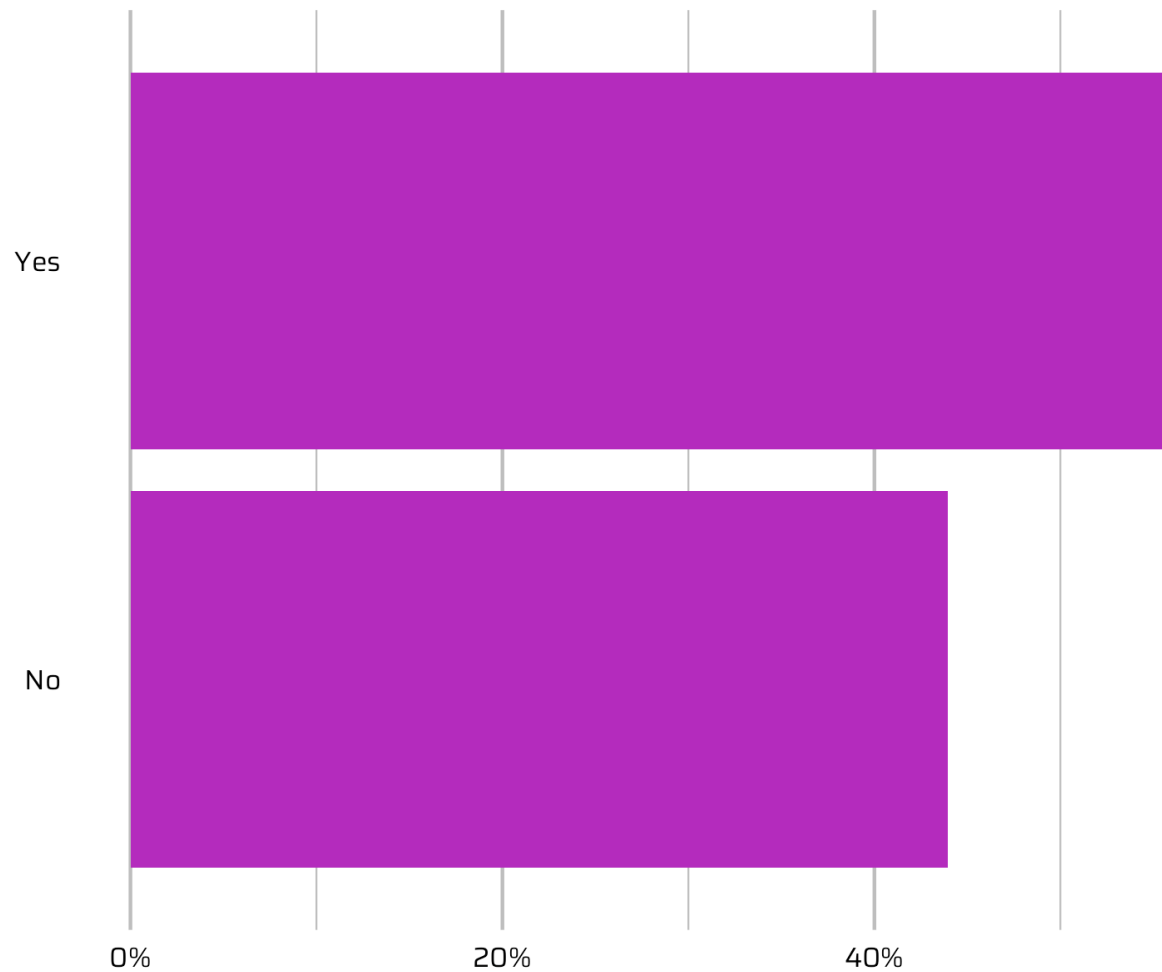
Figure 31: Respondents diagnosed with multiple neurological conditions or not.

Table 30: Respondents diagnosed with multiple neurological conditions or not.

	Respondents	Percentage
Yes	139	56.05
No	109	43.95

Number of non-neurological co-occuring conditions
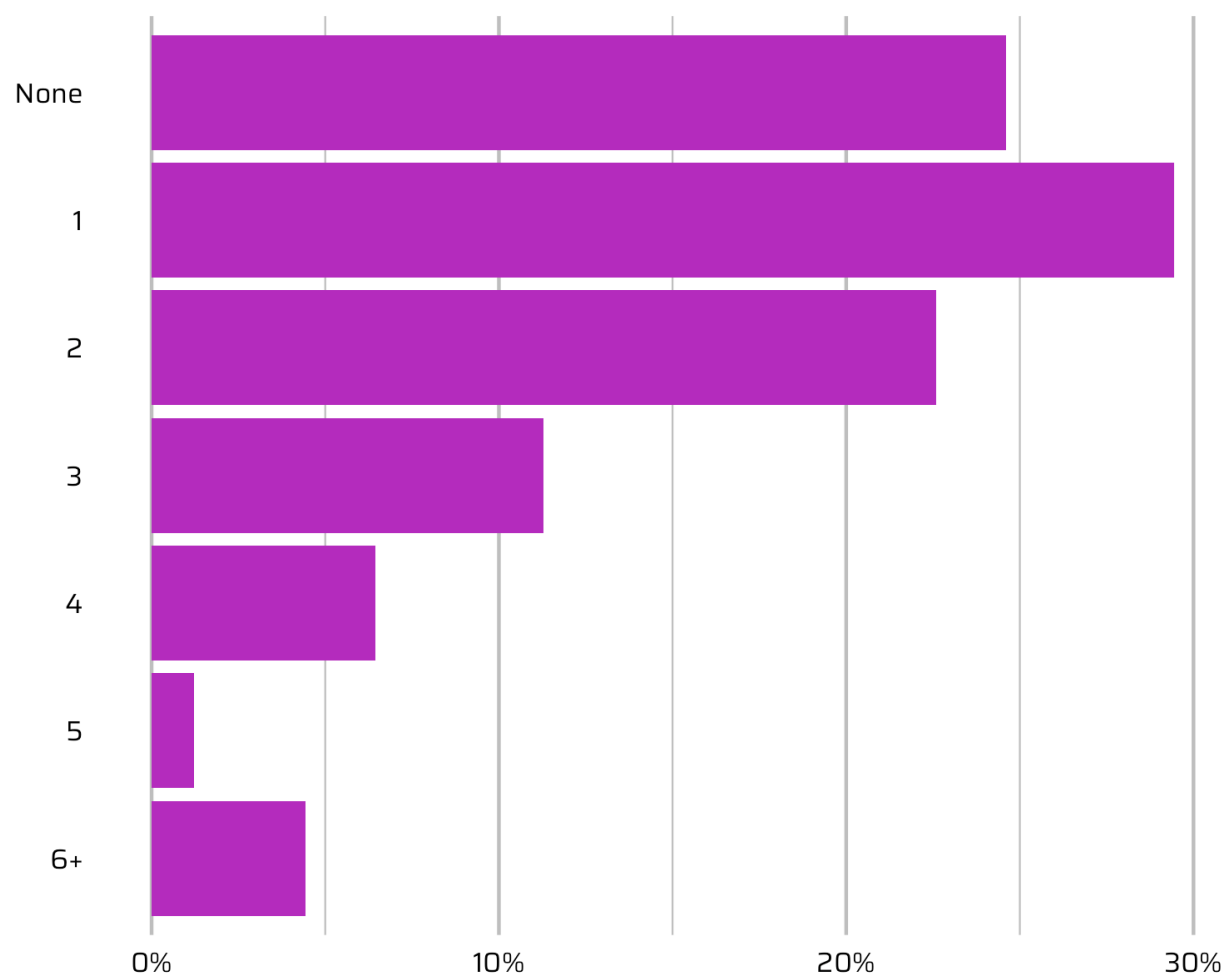
Figure 32: Number of non-neurological conditions that respondents are diagnosed with that co-occur with their neurological condition(s).

Table 31: Number of non-neurological conditions that respondents are diagnosed with that co-occur with their neurological condition(s).

Co-occuring Conditions	Respondents	Percentage
None	61	24.60
1	73	29.44
2	56	22.58
3	28	11.29
4	16	6.45
5	3	1.21
6+	11	4.44

Gender
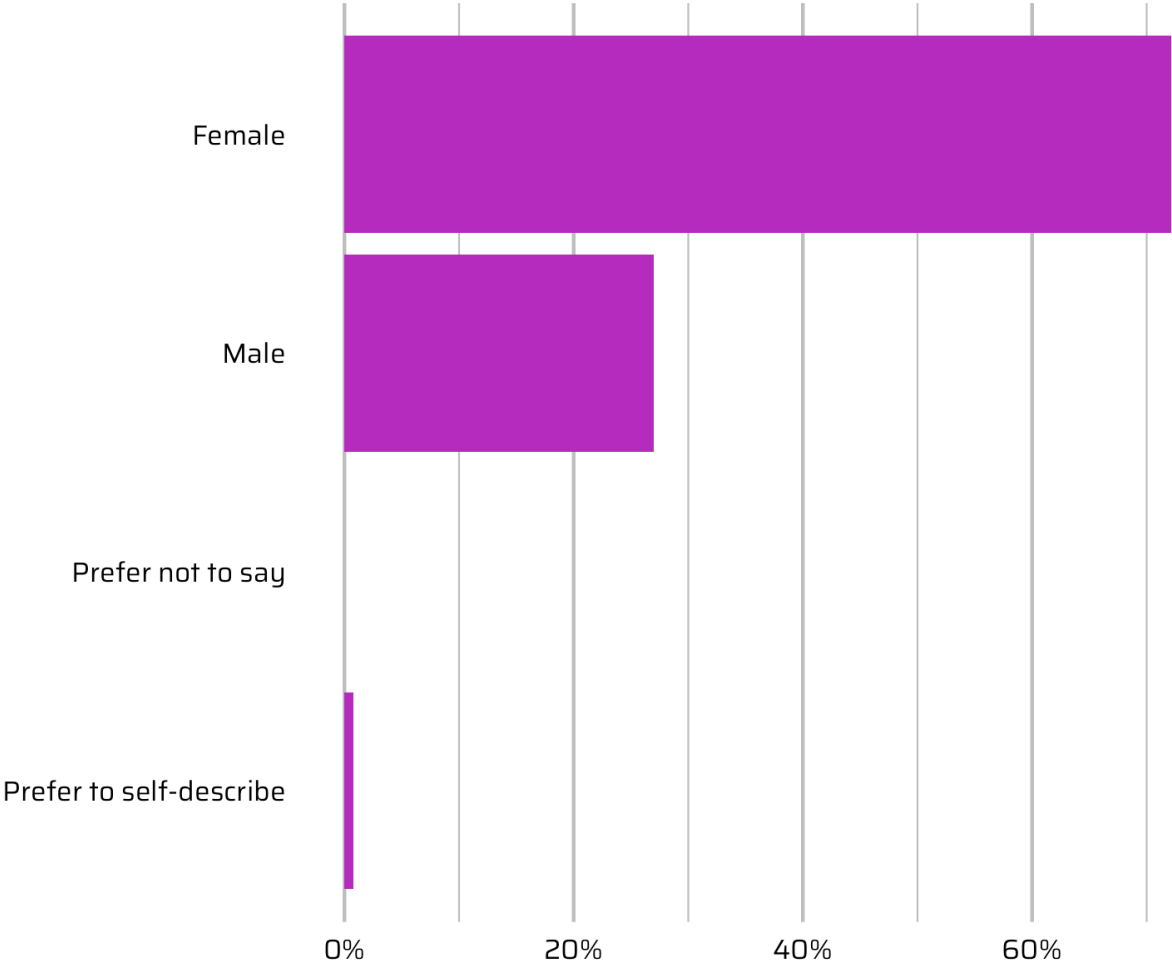
Figure 33: Gender of respondents.

Table 32: Gender of respondents.

Gender	Respondents	Percentage
Female	179	72.18
Male	67	27.02
Prefer not to say	0	0.00
Prefer to self-describe	2	0.81

Sexual orientation
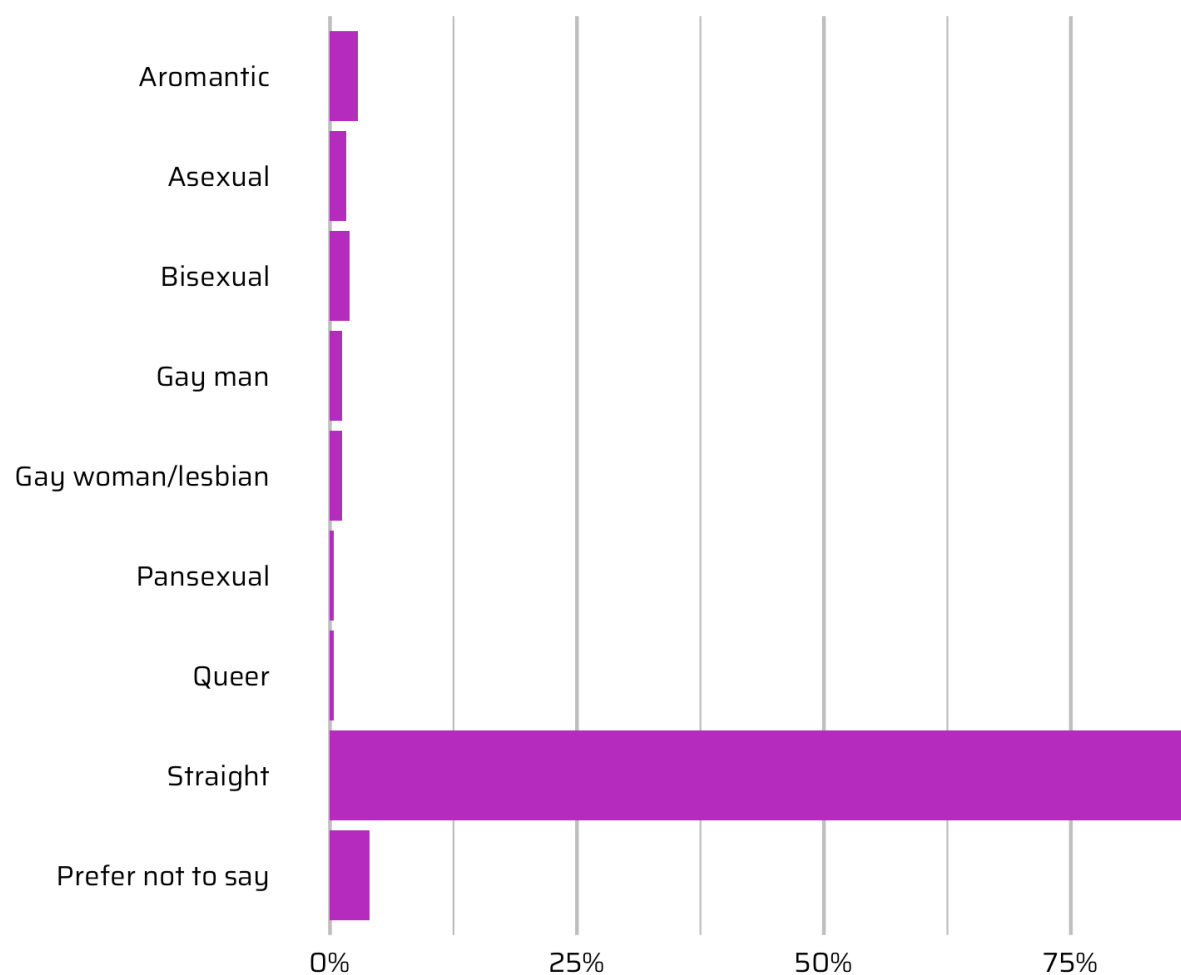
Figure 34: Sexual orientation of respondents.

Table 33: Sexual orientation of respondents.

Sexual orientation	Respondents	Percentage
Aromantic	7	2.82
Asexual	4	1.61
Bisexual	5	2.02
Gay man	3	1.21
Gay woman/lesbian	3	1.21
Pansexual	1	0.40
Queer	1	0.40
Straight	214	86.29
Prefer not to say	10	4.03

Age
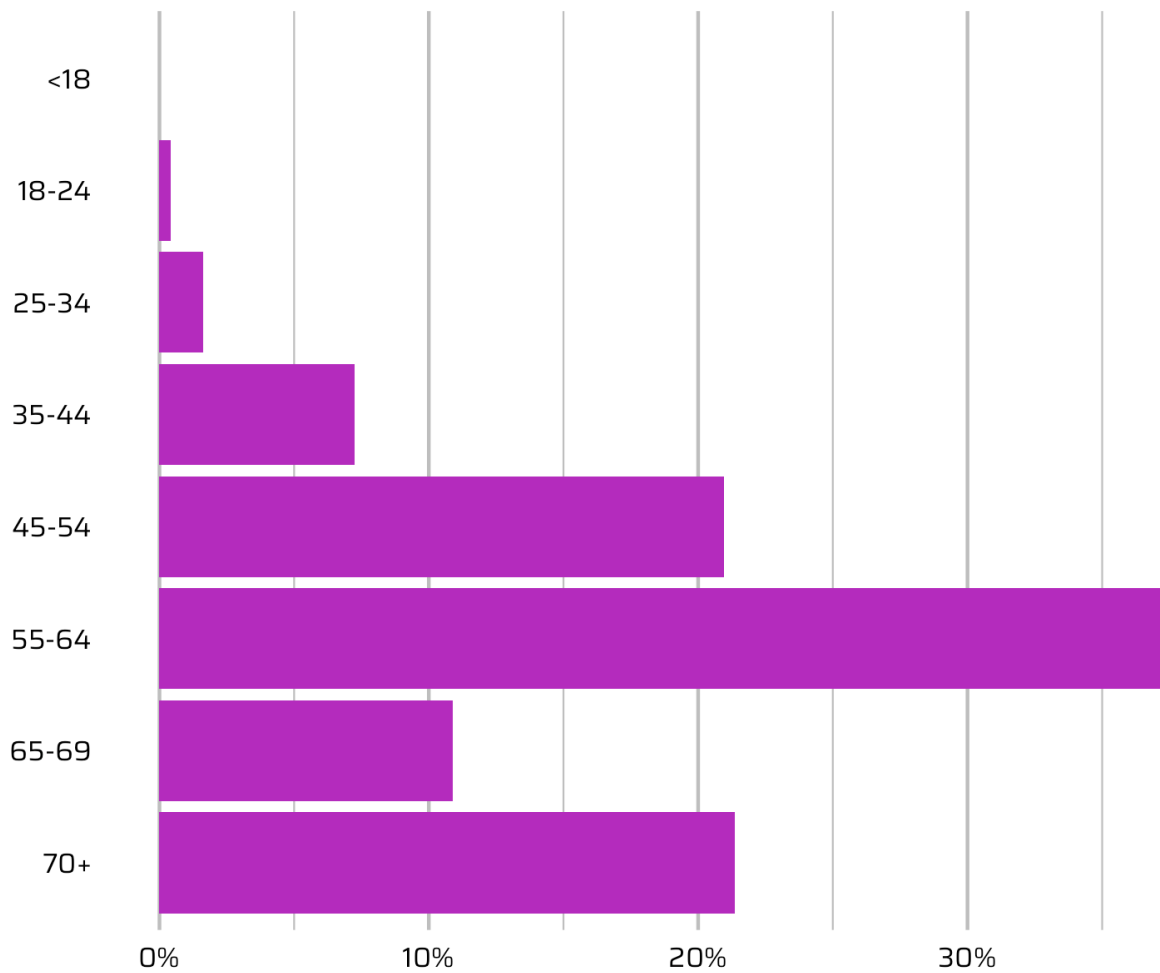
Figure 35: Age of respondents.

Table 34: Age of respondents.

Age	Respondents	Percentage
<18	0	0.00
18-24	1	0.40
25-34	4	1.61
35-44	18	7.26
45-54	52	20.97
55-64	93	37.50
65-69	27	10.89
70+	53	21.37

Ethnicity
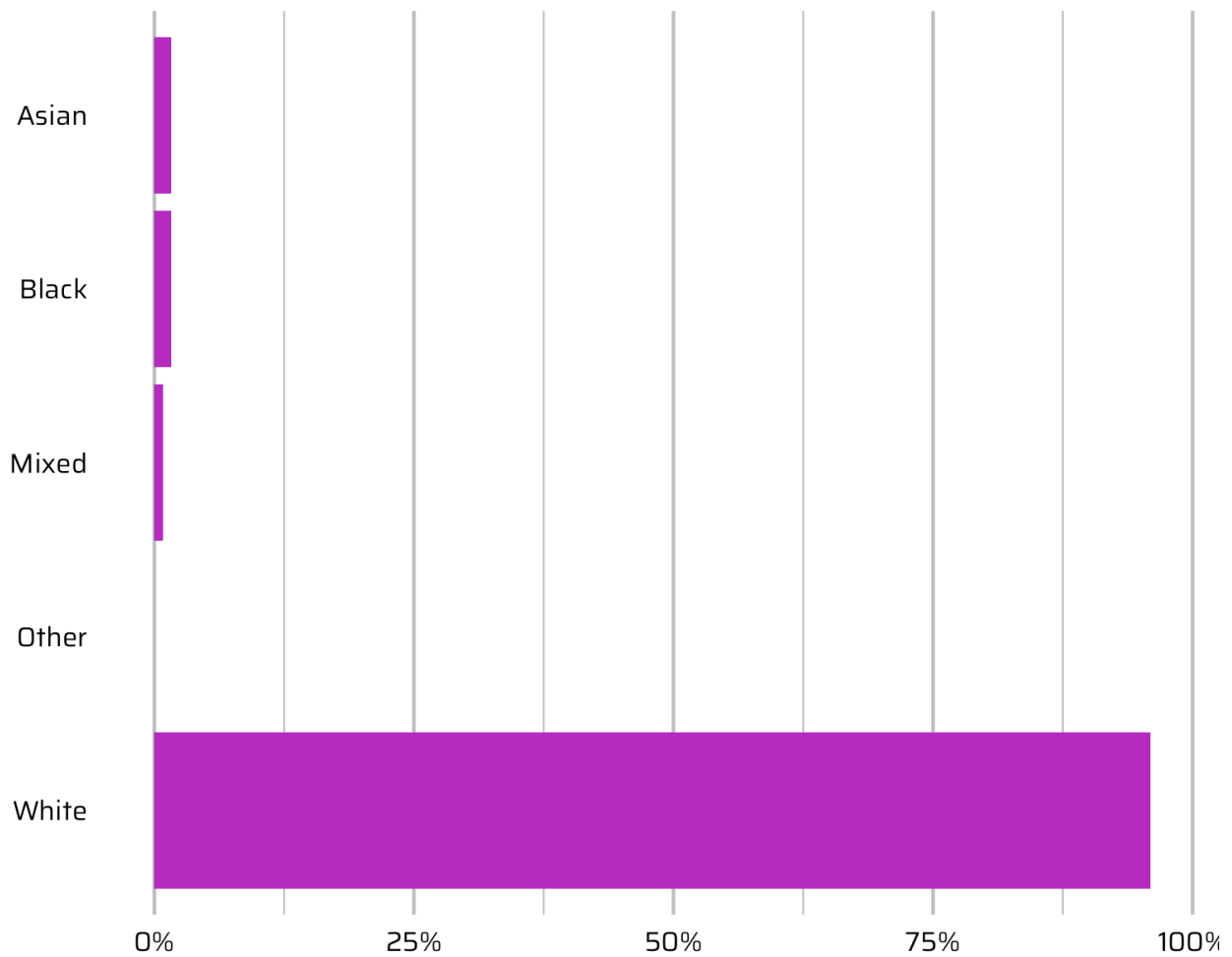
Figure 36: Ethnicity of respondents.

Table 35: Ethnicity of respondents.

Ethnicity	Respondents	Percentage
Asian	4	1.61
Black	4	1.61
Mixed	2	0.81
Other	0	0.00
White	238	95.97

Location of respondents
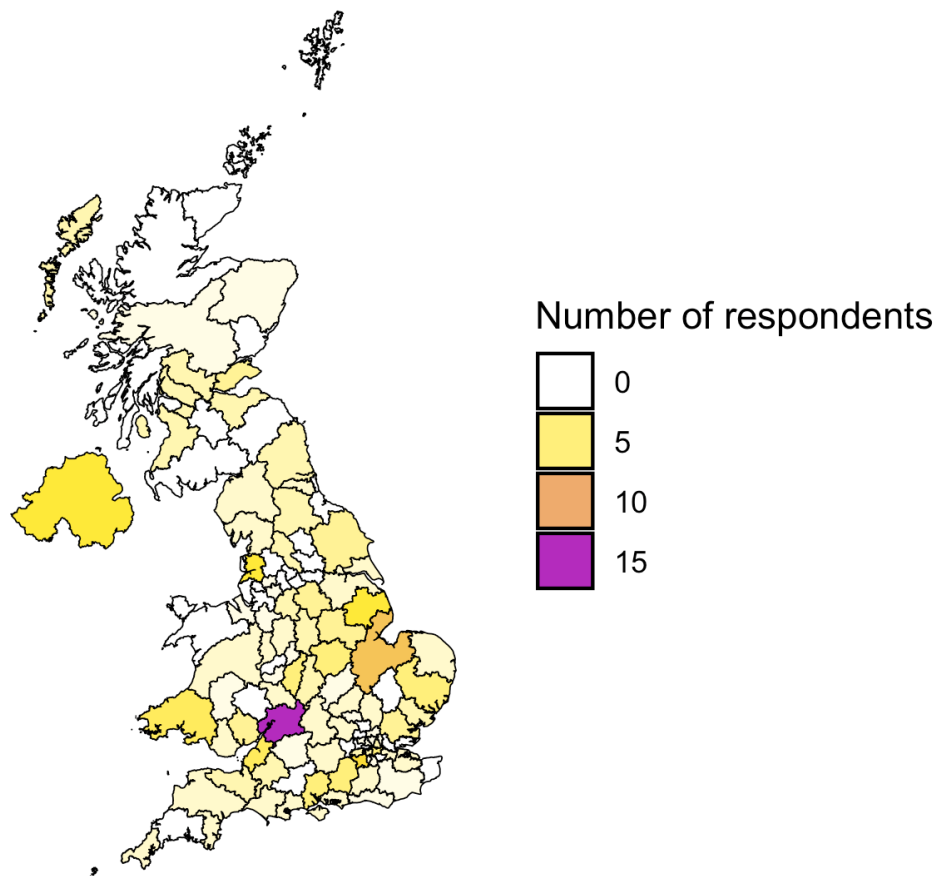
Figure 37: Location of respondents.

Table 36: Location of respondents.

Area Name	Postal Area	Number of respondents
Gloucester	GL	15
Peterborough	PE	9
Kingston upon Thames	KT	8
Lincoln	LN	7
Preston	PR	7
Northern Ireland	BT	7
Bristol	BS	6
Swansea	SA	6

Area Name	Postal Area	Number of respondents
Birmingham	B	5
Guildford	GU	5
Ipswich	IP	5
Leicester	LE	5
London - SE	SE	5
Southampton	SO	5
Chelmsford	CM	4
Kirkcaldy	KY	4
Nottingham	NG	4
Newport	NP	4
Sheffield	S	4
York	YO	4
Bath	BA	3
Bradford	BD	3
Colchester	CO	3
Coventry	CV	3
Derby	DE	3
Darlington	DL	3
London - E	E	3
Edinburgh	EH	3
Falkirk	FK	3
Glasgow	G	3
Outer Hebrides	HS	3
Kilmarnock	KA	3
Newcastle upon Tyne	NE	3
Stockport	SK	3
London - SW	SW	3
Taunton	TA	3
Twickenham	TW	3
Bournemouth	BH	2
Carlisle	CA	2
Cardiff	CF	2
Dartford	DA	2
Durham	DH	2
Doncaster	DN	2
Dorchester	DT	2

Area Name	Postal Area	Number of respondents
Exeter	EX	2
Hemel Hempstead	HP	2
Hull	HU	2
Lancaster	LA	2
Medway	ME	2
Milton Keynes	MK	2
Norwich	NR	2
Oxford	OX	2
Portsmouth	PO	2
Reading	RG	2
Redhill	RH	2
Stevenage	SG	2
Stoke-on-Trent	ST	2
Shrewsbury	SY	2
Telford	TF	2
Torquay	TQ	2
Truro	TR	2
Worcester	WR	2
Aberdeen	AB	1
Bolton	BL	1
Brighton	BN	1
Chester	CH	1
Croydon	CR	1
Crewe	CW	1
Dudley	DY	1
Enfield	EN	1
Harrow	HA	1
Ilford	IG	1
Llandrindod Wells	LD	1
Luton	LU	1
Manchester	M	1
London - N	N	1
Northampton	NN	1
London - NW	NW	1
Perth	PH	1
Sutton	SM	1

Area Name	Postal Area	Number of respondents
Swindon	SN	1
Tonbridge	TN	1
Walsall	WS	1
St Albans	AL	0
Blackburn	BB	0
Bromley	BR	0
Cambridge	CB	0
Canterbury	CT	0
Dundee	DD	0
Dumfries and Galloway	DG	0
London - EC	EC	0
The Fylde	FY	0
Huddersfield	HD	0
Harrogate	HG	0
Hereford	HR	0
Halifax	HX	0
Inverness	IV	0
Kirkwall	KW	0
Liverpool	L	0
Llandudno	LL	0
Leeds	LS	0
Motherwell	ML	0
Oldham	OL	0
Paisley	PA	0
Plymouth	PL	0
Romford	RM	0
Slough	SL	0
Salisbury	SP	0
Sunderland	SR	0
Southend-on-Sea	SS	0
Teviotdale	TD	0
Teeside	TS	0
Uxbridge	UB	0
London - W	W	0
Warrington	WA	0
London - WC	WC	0

Area Name	Postal Area	Number of respondents
Watford	WD	0
Wakefield	WF	0
Wigan	WN	0
Wolverhampton	WV	0
Lerwick	ZE	0

NB: 7 respondents did not provide a UK-based postcode (or did not provide one) and are hence not included in this map and table.

Employment status
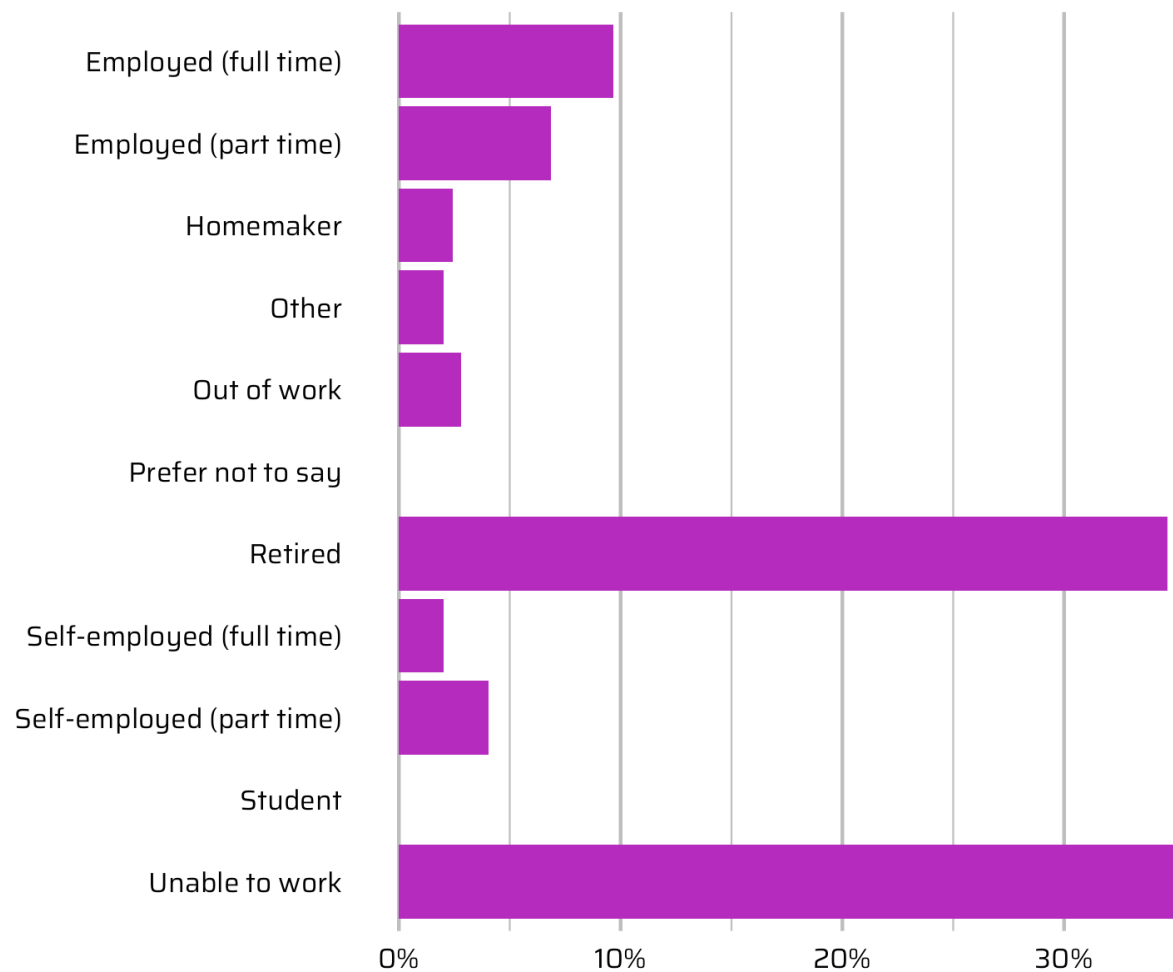
Figure 38: Employment status of respondents.

Table 37: Employment status of respondents.

Employment Status	Respondents	Percentage
Employed (full time)	24	9.68
Employed (part time)	17	6.85
Homemaker	6	2.42
Other	5	2.02
Out of work	7	2.82
Prefer not to say	0	0.00
Retired	86	34.68
Self-employed (full time)	5	2.02
Self-employed (part time)	10	4.03
Student	0	0.00
Unable to work	88	35.48

Number of dependents
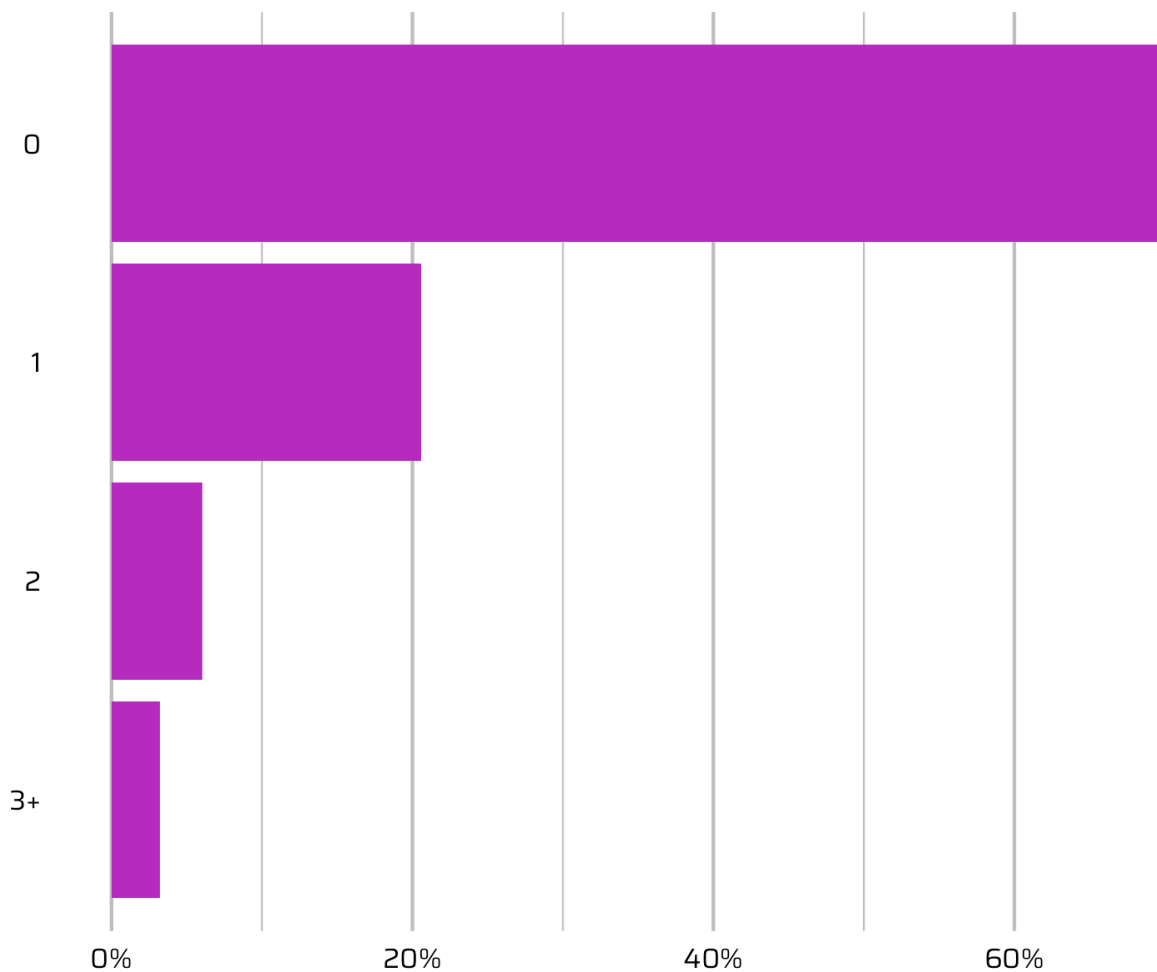
Figure 39: Number of dependents of respondents.

Table 38: Number of dependents of respondents.

Dependents	Respondents	Percentage
0	174	70.16
1	51	20.56
2	15	6.05
3+	8	3.23

Receiving care or support

Figure 40: Number of respondents that receive care and support.

Table 39: Number of respondents that receive care and support.

Home care/support	Respondents	Percentage
No	128	51.61
No but I would like this	34	13.71
Yes and I do not pay	36	14.52
Yes and I pay for this	26	10.48
Not applicable	24	9.68

Appendix A – Survey Questions

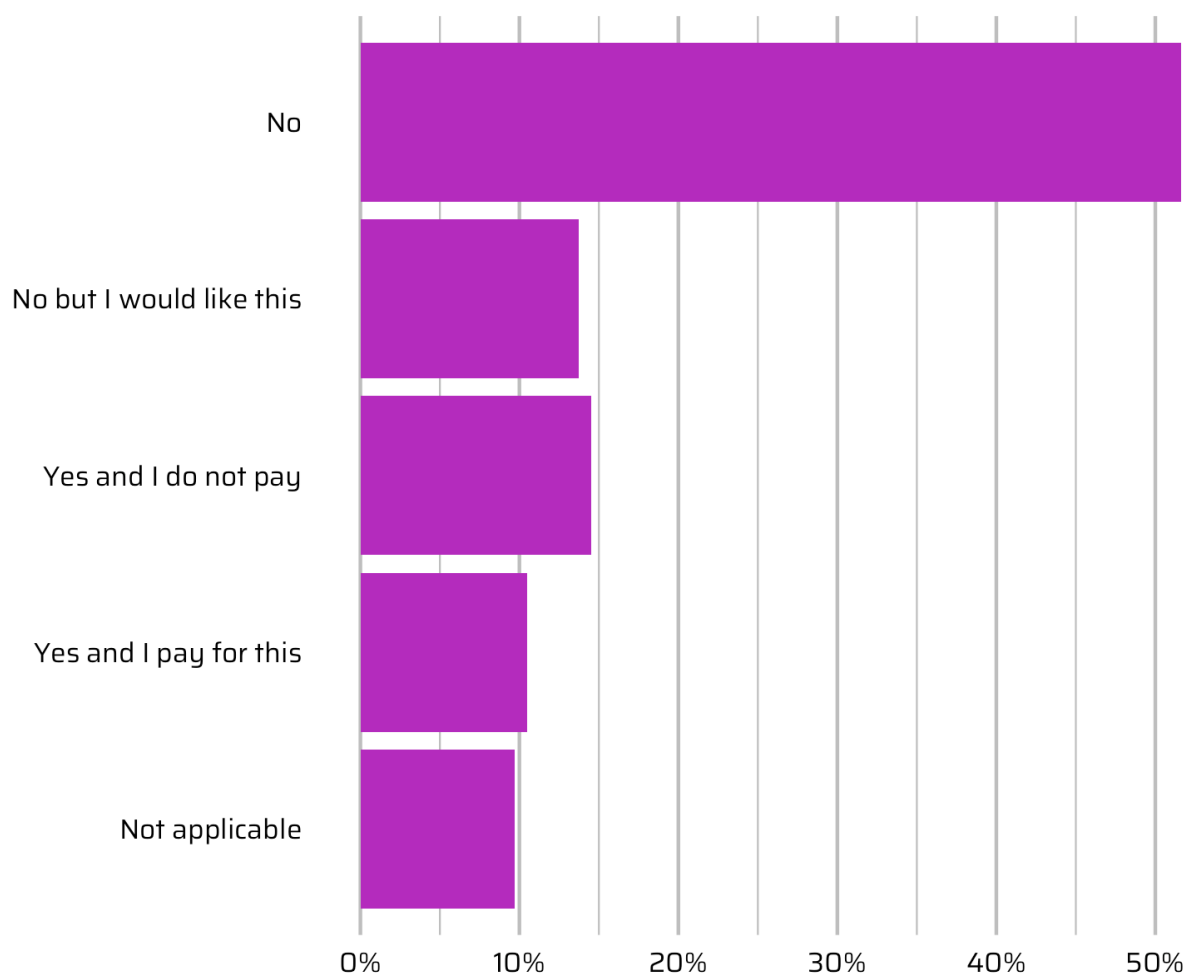| Question	Response options		
Are you filling in this questionnaire for yourself?	Yes	No	
Which year were you diagnosed with your primary neurological condition?	Free text		
About your condition(s)			
Which year were you diagnosed with your primary neurological condition?	Free text		
Please tell us your 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) and/or symptoms you would like to add?	Yes	No	
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 can be done?

In your opinion, how could the UK Government show it is committed to improving the lives of people affected by neurological conditions?	Free text

About your recent experiences of treatment and support.

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 eight 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 helpful 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	
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 you

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 Caribean
	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	
What is your gender?	Male	Female	Prefer to self-describe	Prefer not to say
What is your sexual orientation?	Aromantic	Asexual	Bisexual	Gay man
	Gay woman/lesbian	Pansexual	Queer	Straight (heterosexual)
	Prefer not to say	Other		
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?	1	2	3	4
	5	6+		
Do you receive any care or support at home for your day-to-day life?	Yes and I pay for this	Yes and I do not pay	No but I would like this	No
	Not applicable			

Communicating with you.

What is your first name?	Free text
What is your surname?	Free text
What is your Email Address?	Free text
What is the first line of your address?	Free text
What is your postcode?	Free text

Appendix B – List of Neurological Symptoms & Conditions

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	