



July - August 2023 Insights Report
Travel to appointments and shared experiences



About NeuroLifeNow

NeuroLifeNow was launched in January 2021, enabling people to meaningfully share their daily realities of living with a neurological condition(s) to inform positive change to policy and services.

NeuroLifeNow aims to capture real-time evidence, at scale, from people across the UK. Working directly with people affected by neurological conditions through an innovative web-based technology has been developed and continues to evolve, along with ways for people that do not have access to digital technology to share their daily realities.

Through NeuroLifeNow people share how neurological condition(s) have impacted every aspect of their life. From accessing treatment, care, and support, to home life, work and finances. People do so with confidence that what they share is treated sensitively and handled securely.

Foreword

Neurological conditions are remarkably diverse, affecting individuals from all walks of life. Despite this, this month you told us about shared experiences and symptoms that continue to have a huge impact on lives.

Shared symptoms

Many people reported experiencing **fatigue, muscle spasms, stiffness, weakness, and pain**, affecting the lives of the majority of those surveyed. Additionally, 55% reported experiencing **anxiety**, and 44% reported **depression**. These are battles shared amongst many, but also represent shared opportunities for improvements to care. Access to treatment

Access to timely treatment and care is important for everyone of the 1 in 6 living with a neurological condition. Yet far too many people this month expressed how difficult they find it to travel to their health appointments. **Four out of ten said it was difficult or very difficult to travel**, sometimes because the journey itself could exacerbate their symptoms. People living with multiple conditions, or an additional condition on top of their neurological condition, were more likely to report it was more difficult to travel.

"....getting to the appointments is more stressful than the actual appointment"

"I have to take 2 days off work 1 for appointment then another to get over the travelling."

Others told us about how expensive it was to travel, as well as the challenges of getting the time off to travel to appointments:

"I cannot use public transport and have no friends or family to take me. Currently I pay for carer to take me which is expensive."

"I have to use patient transport and have to be ready for pickup 4 hours before appointment time and return journey can only be booked once appointment concluded and have to again wait up to 4 hours for pickup to travel home. Just finished 30 sessions of treatment and each day was between 8-13 hours for 20 minutes of treatment."

"I have to travel by train, and it is a 90 minute journey each way, so I have to take a whole day off work to get to an appointment that might only be 10 minutes long"

Drop in overall experience of healthcare

Really worryingly, the proportion of people reporting **a good or very good overall experience of healthcare has dropped from May and June (from 37% to 27%)**. A decrease in satisfaction is a clear signal that our healthcare system needs to change.

"2 year wait so paid private"

"Can't get in touch with the team. I seem to have been sent into a black hole"

Many people reported not being able to access healthcare when they needed to.

Many people told us this was due to long waiting lists, an inability to attend appointments due to work commitments, mobility related problems and administration issues/complications.

"I was offered an appointment, but my specialist didn't turn up"

"I rang my neurologist's secretary after receiving a letter, cancelling my botox treatment appt and pushing that appt back 3 months. She explained that this was due to accommodating staff holidays. The secretary very kindly rang me a couple of weeks later, to offer me an ad hoc appointment, one month later than my original appt. Although grateful for this, it was deeply upsetting and distressing to receive that extremely lengthy appt delay."

Together, we have called for a much-needed change to address many of the issues highlighted here. Since last year, more than 100 organisations and 19,000 people across the country have called on UK Government's to establish a 'Neuro Taskforce' to address the shortcomings in treatment and care for the 1 in 6 living with a neurological condition in this country. We know the UK Government is considering this proposal – quite frankly, a commitment to a Taskforce, and to change, cannot happen quick enough.

The Brain & Spine Foundation neuroscience nurses are here for you, providing practical and emotional support relating to any neurological condition(s). You can get in touch 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)

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Key Findings

- **746 people responded** to the July/August survey. **157 conditions** and neurological symptoms were represented. The most common were multiple sclerosis, dystonia and functional neurological disorder. **50% lived with multiple conditions.**
- The most reported issues and symptoms were **fatigue (80%), muscle spasms, stiffness and weakness (70%), and pain (61%),**
- **55% reported anxiety, and 44% reported depression,** which is in line with the findings of our previous surveys.
- **50% of people said it was difficult or very difficult to travel to their health appointments** for their neurological condition. People with multiple neurological conditions, or conditions in addition to their neurological condition, were more likely to report difficulty in travelling to their appointments.
- **30% of respondents said it took more than an hour to travel to their health or care appointments** for their neurological conditions. People with multiple neurological conditions were more likely to travel **more than two hours compared to those with one condition.**
- When people were unable to speak to anyone, **32% went without any healthcare input at all.**
- Multiple reasons were cited as making the journey problematic, including **poor availability of accessible facilities; cost inappropriate/non-existent public transport; and the journey aggravating symptoms** associated with their condition.
- 27% of respondents said their **overall experience of healthcare** was good or very good in July and August (**10% down from May/June**).
- **Many people reported not being able to access healthcare when they needed to.** This was due to long waiting lists, an inability to attend appointments due to work commitments or mobility related problems or administration issues/complications.

Shared issues and symptoms

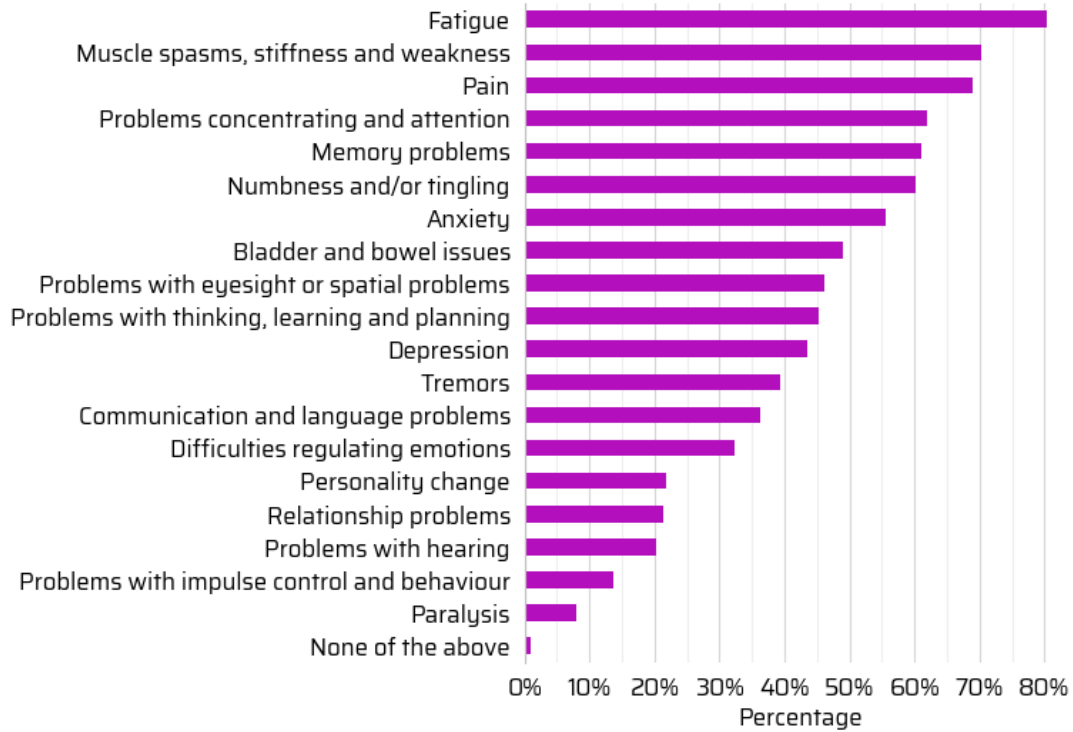


Figure 1: Shared issues and symptoms.

Table 1: Shared issues and symptoms.

Symptom	Respondents	Percentage
Fatigue	601	80.35
Muscle spasms, stiffness and weakness	526	70.32
Pain	516	68.98
Problems concentrating and attention	464	62.03
Memory problems	456	60.96
Numbness and/or tingling	451	60.29
Anxiety	415	55.48
Bladder and bowel issues	366	48.93
Problems with eyesight or spatial problems	345	46.12
Problems with thinking, learning and planning	339	45.32
Depression	326	43.58

Tremors	294	39.3
Communication and language problems	271	36.23
Difficulties regulating emotions	242	32.35
Personality change	163	21.79
Relationship problems	159	21.26
Problems with hearing	152	20.32
Problems with impulse control and behaviour	102	13.64
Paralysis	60	8.02
None of the above	7	0.94

Getting to appointments.

Travel time to get to appointments.

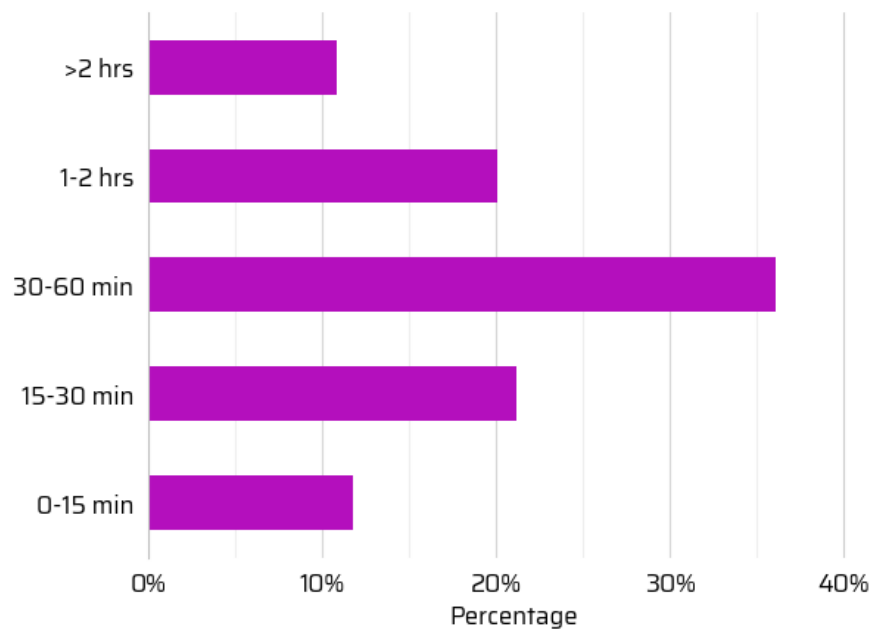


Figure 2: Travel time to get to appointments.

Table 2: Travel time to get to appointments.

Duration	Respondents	Percentage
>2 hrs	81	10.86

1-2 hrs	150	20.11
30-60 min	269	36.06
15-30 min	158	21.18
0-15 min	88	11.8

Travel time to get to appointments among people with vs without multiple neurological conditions.

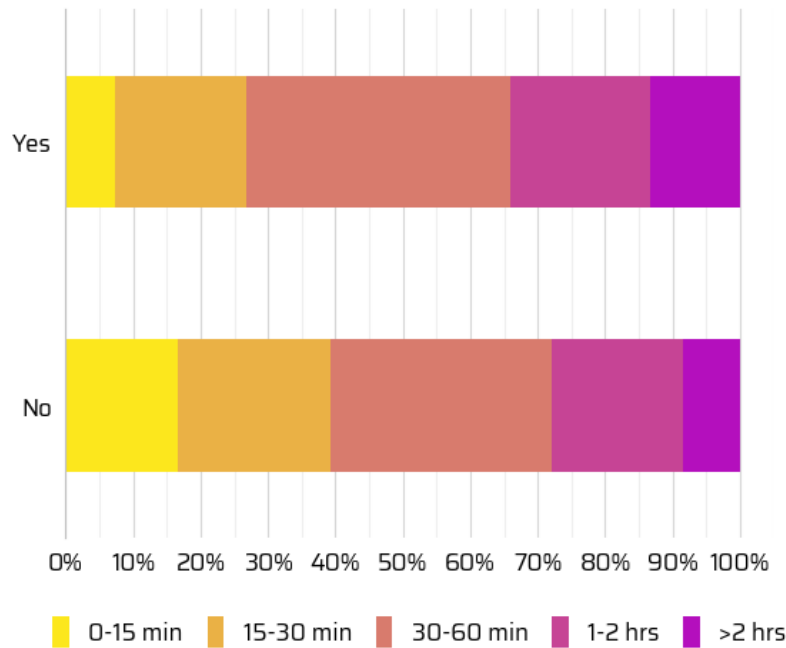


Figure 3: Travel time to get to appointments among people with vs without multiple neurological conditions.

Table 3: Travel time to get to appointments among people with vs without multiple neurological conditions.

Multiple neurological conditions	Duration	Respondents	Percentage
Yes	>2 hrs	50	13.4
	1-2 hrs	77	20.64
	30-60 min	146	39.14
	15-30 min	73	19.57

	0-15 min	27	7.24
	>2 hrs	31	8.4
	1-2 hrs	72	19.51
No	30-60 min	121	32.79
	15-30 min	84	22.76
	0-15 min	61	16.53

Travel time to get to appointments among people with vs without co-occurring non-neurological conditions.

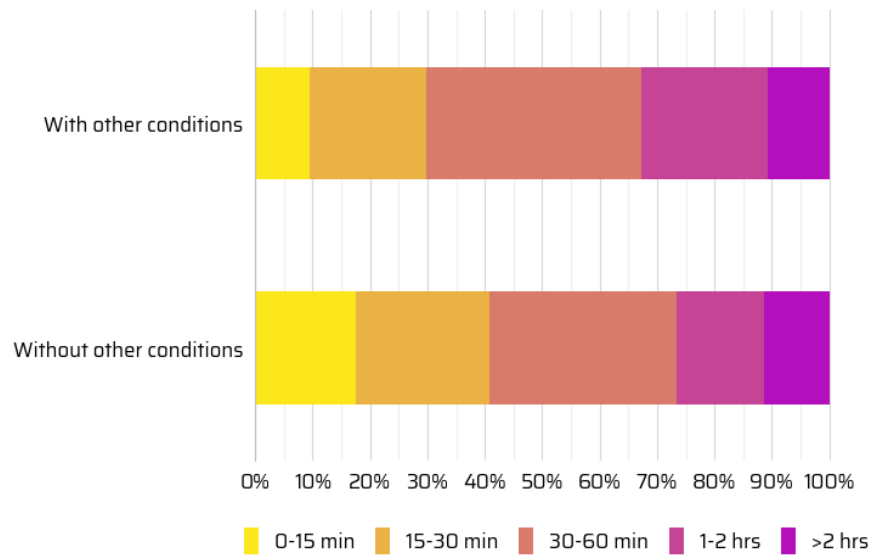


Figure 4: Travel time to get to appointments among people with vs without co-occurring non-neurological conditions.

Table 4: Travel time to get appointments among people with vs without co-occurring non-neurological conditions.

Co-occurring conditions	Duration	Respondents	Percentage
	>2 hrs	57	10.65
With other conditions	1-2 hrs	118	22.06
	30-60 min	200	37.38
	15-30 min	109	20.37

	0-15 min	51	9.53
	>2 hrs	24	11.37
	1-2 hrs	32	15.17
Without other conditions	30-60 min	69	32.7
	15-30 min	49	23.22
	0-15 min	37	17.54

Travel time to get to appointments among people in different age groups.

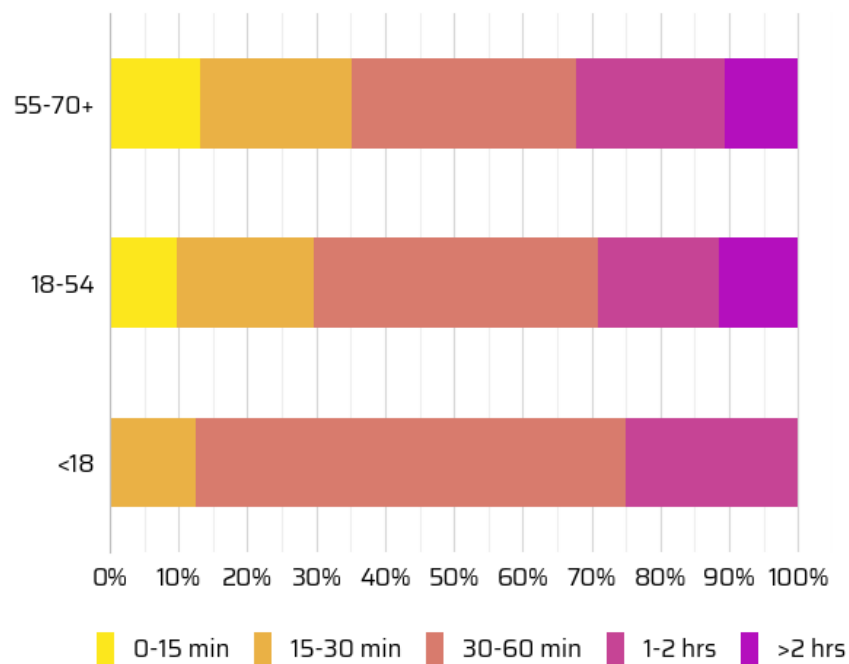


Figure 5: Travel time to get to appointments among people in different age groups.

Table 5: Travel time to get to appointments among people in different age groups.

Age	Duration	Respondents	Percentage
	>2 hrs	50	10.66
	1-2 hrs	101	21.54
55-70+	30-60 min	153	32.62
	15-30 min	103	21.96
	0-15 min	62	13.22

18-54	>2 hrs	31	11.52
	1-2 hrs	47	17.47
	30-60 min	111	41.26
	15-30 min	54	20.07
	0-15 min	26	9.67
<18	>2 hrs	0	0.0
	1-2 hrs	2	25.0
	30-60 min	5	62.5
	15-30 min	1	12.5
	0-15 min	0	0.0

Travel time to get to appointments among people of different genders.

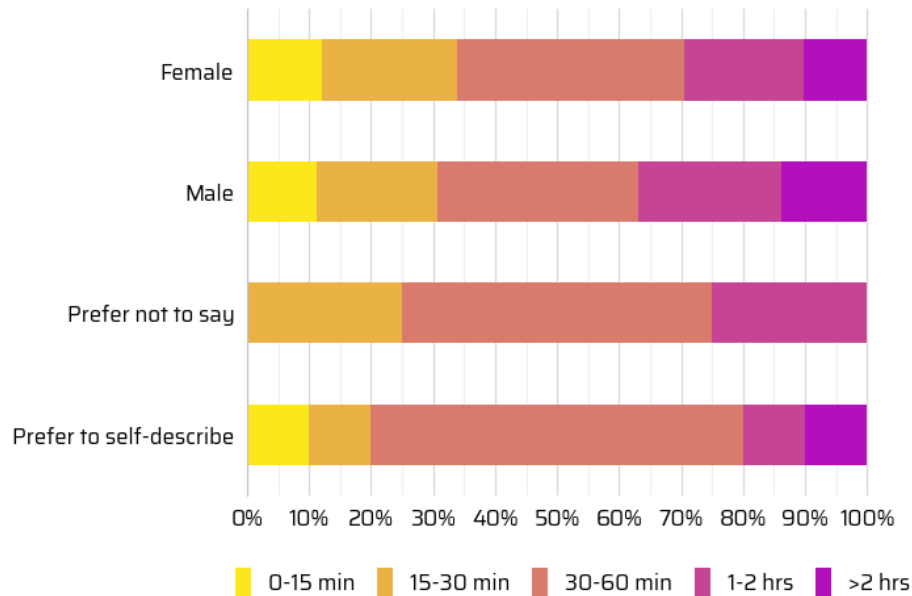


Figure 6: Travel time to get to appointments among people of different genders.

Table 6: Travel time to get to appointments among people of different genders.

Gender	Duration	Respondents	Percentage
Female	>2 hrs	58	10.14
	1-2 hrs	111	19.41

	30-60 min	209	36.54
	15-30 min	125	21.85
	0-15 min	69	12.06
	>2 hrs	22	13.75
	1-2 hrs	37	23.12
Male	30-60 min	52	32.5
	15-30 min	31	19.38
	0-15 min	18	11.25
	>2 hrs	0	0.0
	1-2 hrs	1	25.0
Prefer not to say	30-60 min	2	50.0
	15-30 min	1	25.0
	0-15 min	0	0.0
	>2 hrs	1	10.0
	1-2 hrs	1	10.0
Prefer to self-describe	30-60 min	6	60.0
	15-30 min	1	10.0
	0-15 min	1	10.0

Time to travel to appointments among people with different employment status.

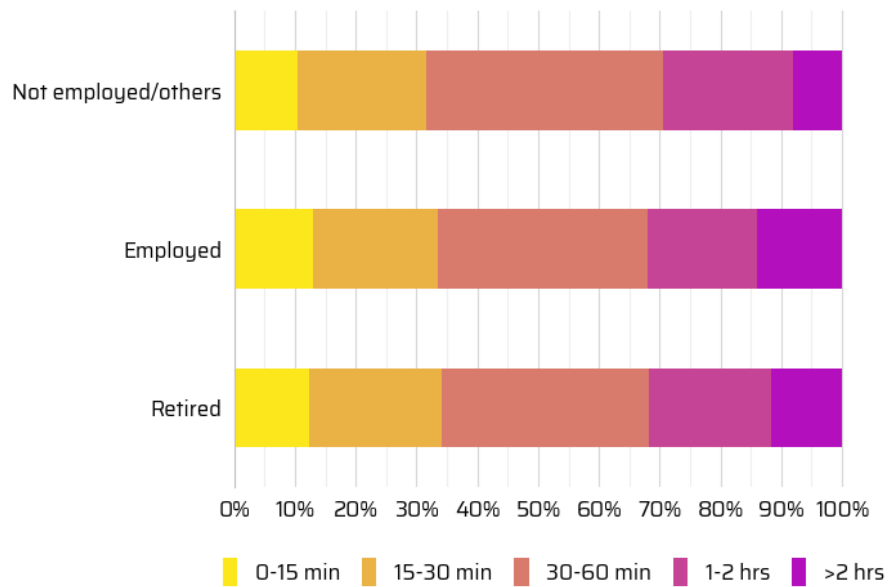


Figure 7: Travel time to get to appointments among people with different employment status.

Table 7: Travel time to get to appointments among people with different employment status.

Employment status	Duration	Respondents	Percentage
Not employed/others	>2 hrs	23	8.07
	1-2 hrs	61	21.4
	30-60 min	111	38.95
	15-30 min	60	21.05
	0-15 min	30	10.53
Employed	>2 hrs	27	13.92
	1-2 hrs	35	18.04
	30-60 min	67	34.54
	15-30 min	40	20.62
	0-15 min	25	12.89
Retired	>2 hrs	31	11.61
	1-2 hrs	54	20.22
	30-60 min	91	34.08

15-30 min	58	21.72
0-15 min	33	12.36

Time to travel to appointments among people with vs without dependents.

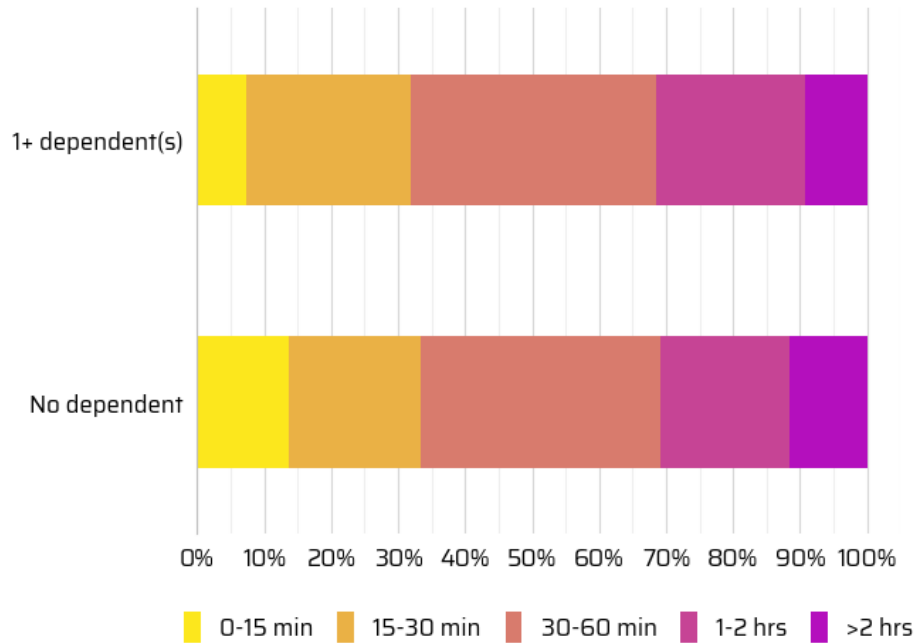


Figure 8: Travel time to get to appointments among people with vs without dependents.

Table 8: Travel time to get to appointments among people with vs without dependents.

Number of dependents	Duration	Respondents	Percentage
1+ dependent(s)	>2 hrs	20	9.26
	1-2 hrs	48	22.22
	30-60 min	79	36.57
	15-30 min	53	24.54
	0-15 min	16	7.41
No dependent	>2 hrs	61	11.51
	1-2 hrs	102	19.25
	30-60 min	190	35.85
	15-30 min	105	19.81

0-15 min	72	13.58
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Travel time to get to appointments among people with different extent of mental health needs met.

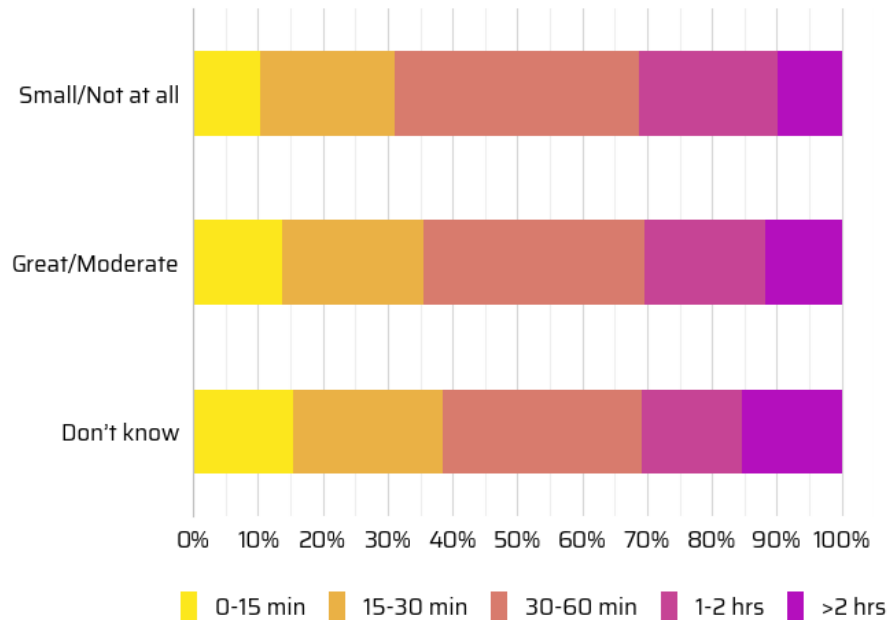


Figure 9: Travel time to get to appointments among people with different extent of mental health needs met.

Table 9: Travel time to get to appointments among people with different extent of mental health needs met.

Needs met	Duration	Respondents	Percentage
Small/Not at all	>2 hrs	45	9.91
	1-2 hrs	97	21.37
	30-60 min	171	37.67
	15-30 min	94	20.7
	0-15 min	47	10.35
Great/Moderate	>2 hrs	28	11.67
	1-2 hrs	45	18.75
	30-60 min	82	34.17

	15-30 min	52	21.67
	0-15 min	33	13.75
	>2 hrs	8	15.38
	1-2 hrs	8	15.38
Don't know	30-60 min	16	30.77
	15-30 min	12	23.08
	0-15 min	8	15.38

Difficulty travelling to appointments.

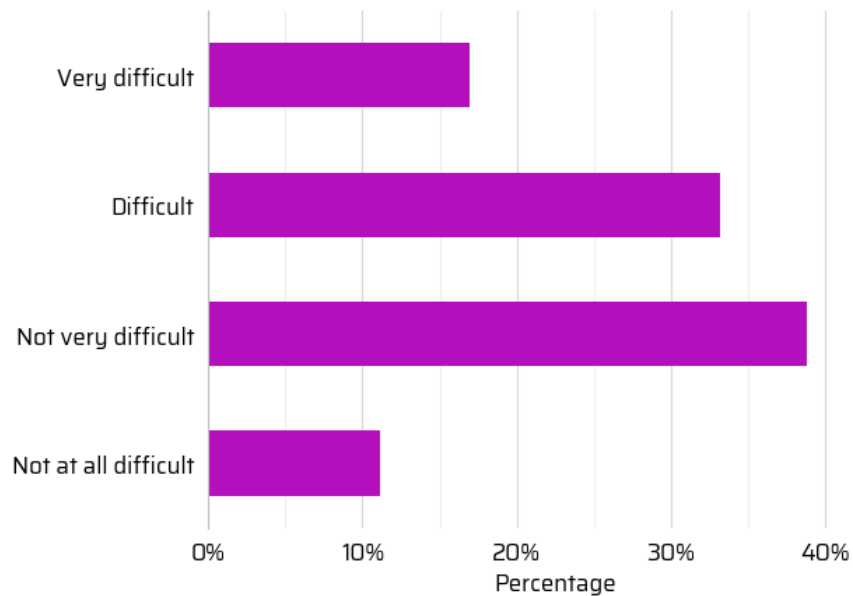


Figure 10: Difficulty travelling to appointments.

Table 10: Difficulty travelling to appointments.

Difficulty	Respondents	Percentage
Very difficult	126	16.91
Difficult	247	33.15
Not very difficult	289	38.79
Not at all difficult	83	11.14

Difficulty travelling to appointments among people with vs without multiple neurological conditions.

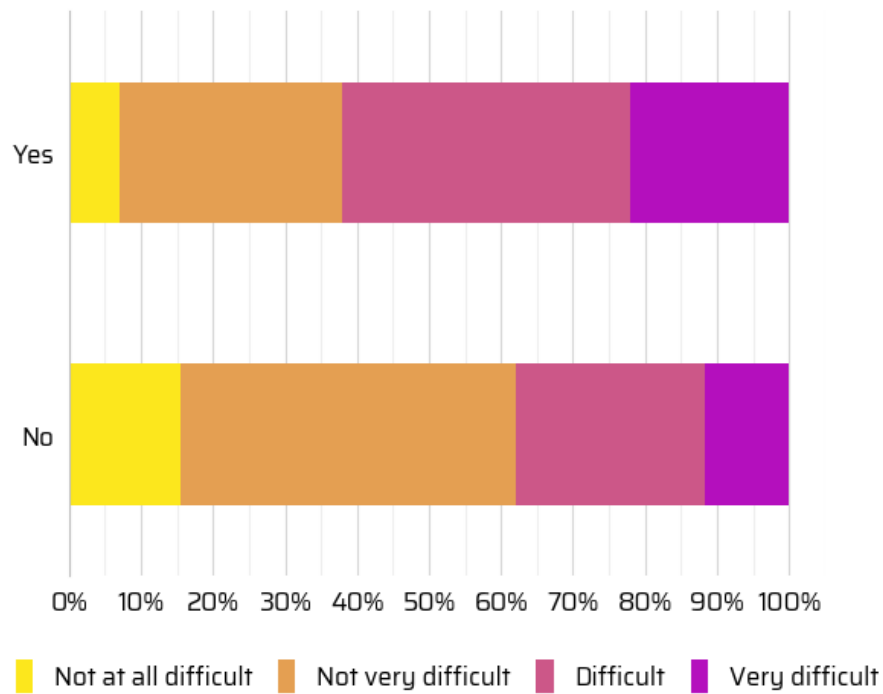


Figure 11: Difficulty travelling to appointments among people with vs without multiple neurological conditions.

Table 11: Difficulty travelling to appointments among people with vs without multiple neurological conditions.

Multiple neurological conditions	Difficulty	Respondents	Percentage
Yes	Very difficult	82	22.04
	Difficult	149	40.05
	Not very difficult	115	30.91
	Not at all difficult	26	6.99
No	Very difficult	43	11.65
	Difficult	97	26.29
	Not very difficult	172	46.61
	Not at all difficult	57	15.45

Difficulty travelling to appointments among people with vs without co-occurring non-neurological conditions.

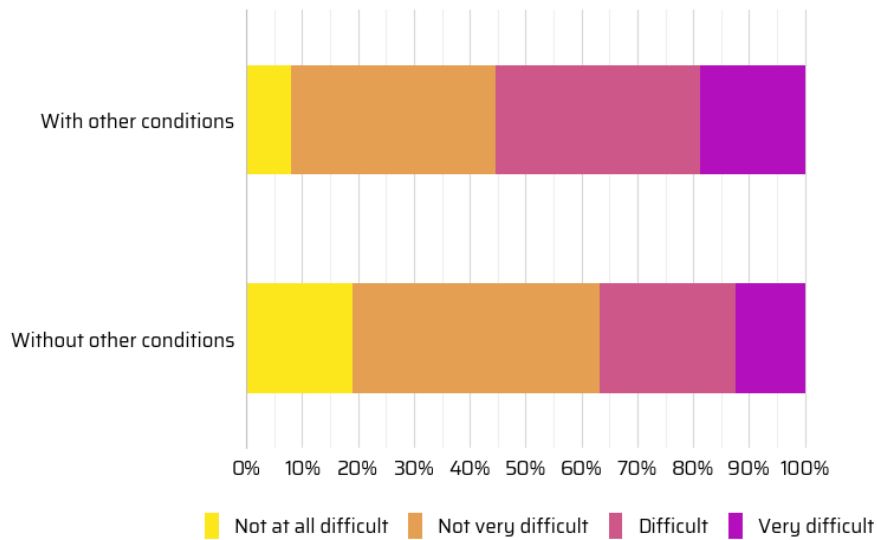


Figure 12: Difficulty travelling to appointments among people with vs without co-occurring non-neurological conditions.

Table 12: Difficulty travelling to appointments among people with vs without co-occurring non-neurological conditions.

Co-occurring conditions	Difficulty	Respondents	Percentage
With other conditions	Very difficult	100	18.69
	Difficult	196	36.64
	Not very difficult	196	36.64
	Not at all difficult	43	8.04
Without other conditions	Very difficult	26	12.38
	Difficult	51	24.29
	Not very difficult	93	44.29
	Not at all difficult	40	19.05

Difficulty travelling to appointments among people in different age groups.

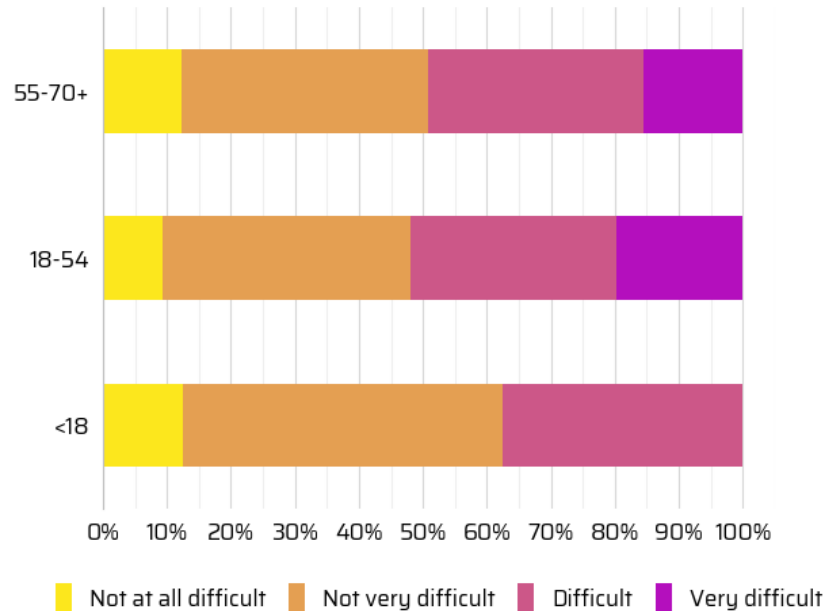


Figure 13: Difficulty travelling to appointments among people in different age groups.

Table 13: Difficulty travelling to appointments among people in different age groups.

Age	Difficulty	Respondents	Percentage
55-70+	Very difficult	73	15.6
	Difficult	157	33.55
	Not very difficult	181	38.68
	Not at all difficult	57	12.18
18-54	Very difficult	53	19.7
	Difficult	87	32.34
	Not very difficult	104	38.66
	Not at all difficult	25	9.29
<18	Very difficult	0	0.0
	Difficult	3	37.5
	Not very difficult	4	50.0
	Not at all difficult	1	12.5

Difficulty travelling to appointments among people of different genders.

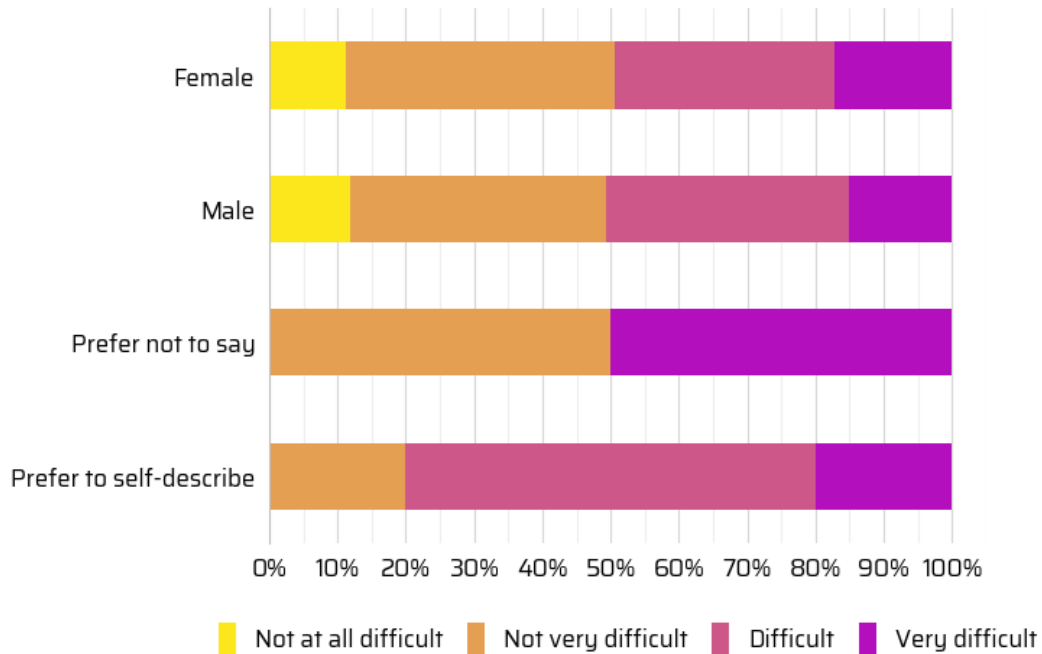


Figure 14: Difficulty travelling to appointments among people of different genders.

Table 14: Difficulty travelling to appointments among people of different genders.

Gender	Difficulty	Respondents	Percentage
Female	Very difficult	98	17.16
	Difficult	184	32.22
	Not very difficult	225	39.4
	Not at all difficult	64	11.21
Male	Very difficult	24	15.0
	Difficult	57	35.62
	Not very difficult	60	37.5
	Not at all difficult	19	11.88
Prefer not to say	Very difficult	2	50.0
	Difficult	0	0.0
	Not very difficult	2	50.0
	Not at all difficult	0	0.0

Prefer to self-describe	Very difficult	2	20.0
	Difficult	6	60.0
	Not very difficult	2	20.0
	Not at all difficult	0	0.0

Difficulty travelling to appointments among people with different employment status.

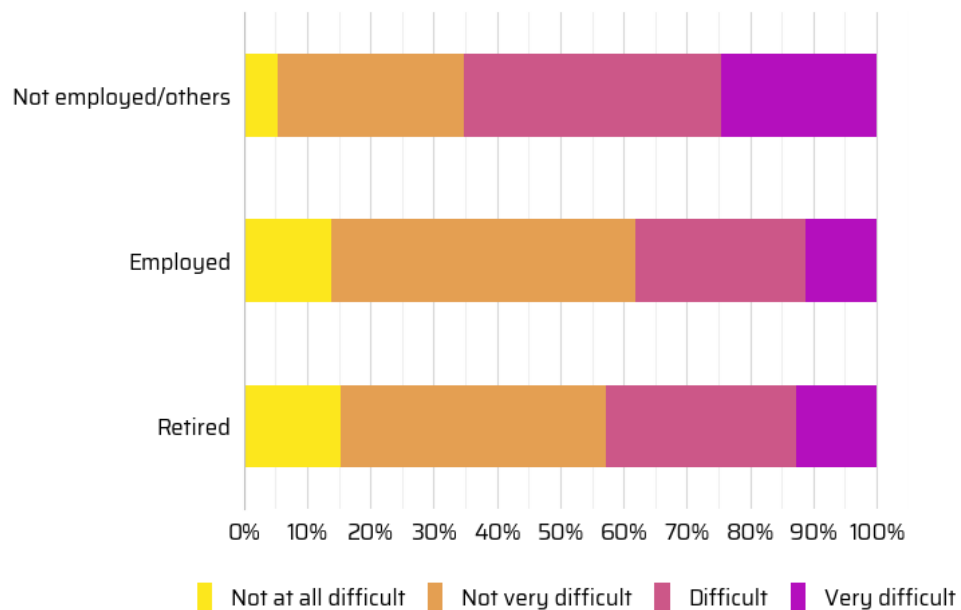


Figure 15: Difficulty travelling to appointments among people with different employment status.

Table 15: Difficulty travelling to appointments among people with different employment status.

Employment status	Difficulty	Respondents	Percentage
Not employed/other	Very difficult	70	24.65
	Difficult	115	40.49
	Not very difficult	84	29.58
	Not at all difficult	15	5.28
Employed	Very difficult	22	11.34
	Difficult	52	26.8

Retired	Not very difficult	93	47.94
	Not at all difficult	27	13.92
	Very difficult	34	12.73
	Difficult	80	29.96
	Not very difficult	112	41.95
	Not at all difficult	41	15.36

Difficulty travelling to appointments among people with vs without dependents.

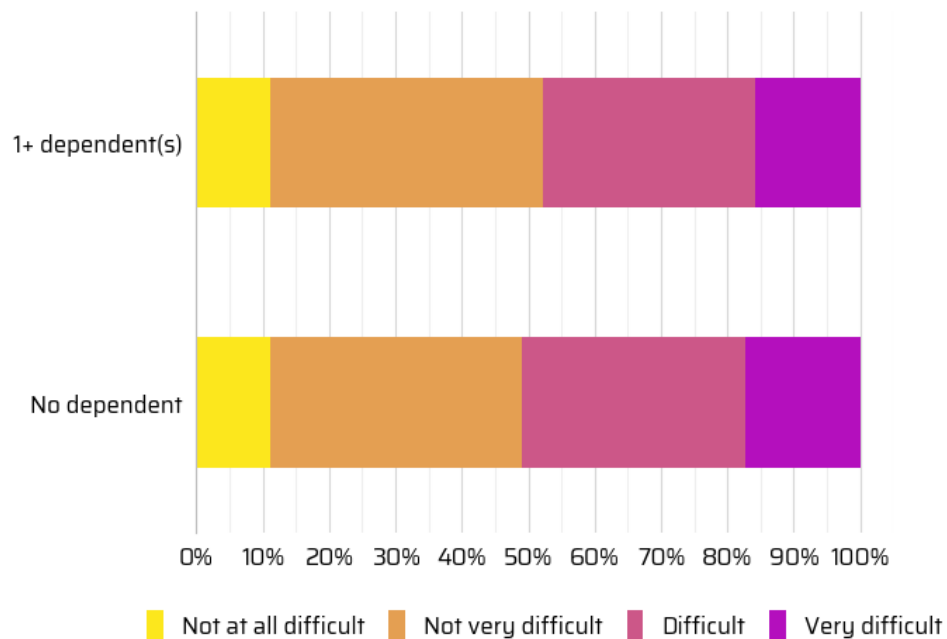


Figure 16: Difficulty travelling to appointments among people with vs without dependents.

Table 16: Difficulty travelling to appointments among people with vs without dependents.

Number of dependents	Difficulty	Respondents	Percentage
1+ dependent(s)	Very difficult	34	15.74
	Difficult	69	31.94
	Not very difficult	89	41.2
	Not at all difficult	24	11.11

No dependent	Very difficult	92	17.39
	Difficult	178	33.65
	Not very difficult	200	37.81
	Not at all difficult	59	11.15

Difficulty travelling to appointments among people with different extent of mental health needs met.

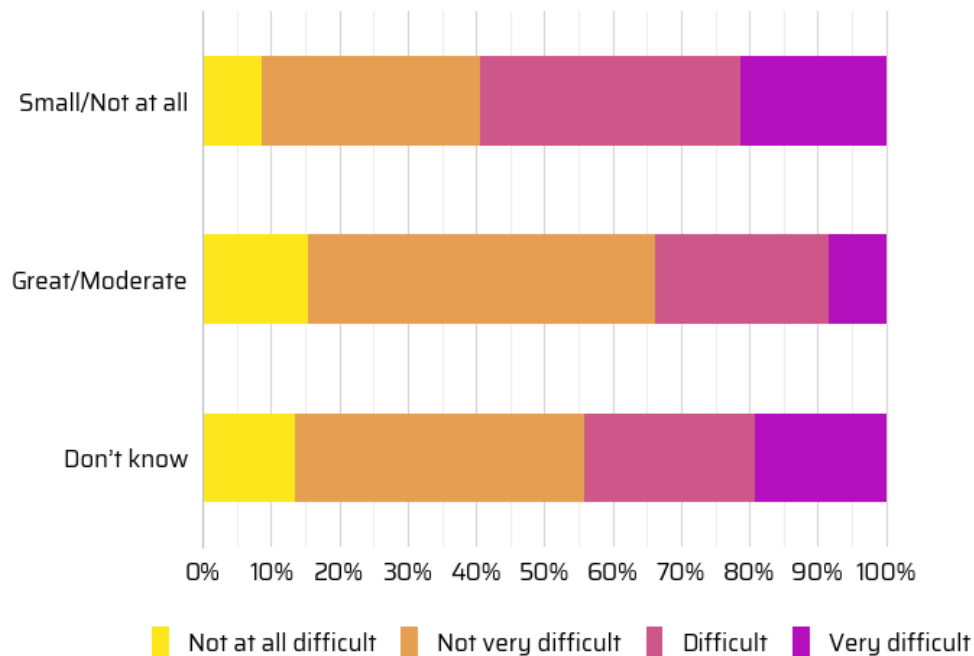


Figure 17: Difficulty travelling to appointments among people with different extent of mental health needs met.

Table 17: Difficulty travelling to appointments among people with different extent of mental health needs met.

Needs met	Difficulty	Respondents	Percentage
Small/Not at all	Very difficult	96	21.19
	Difficult	173	38.19
	Not very difficult	145	32.01
	Not at all difficult	39	8.61
Great/Moderate	Very difficult	20	8.33

Thematic analysis

A thematic analysis was conducted for responses to the question. The following themes have emerged:

- **Theme 1: Public transport.**
 - Public transport are not reliable or non-existent.
 - No direct public transport/multiple changes.
 - Accessibility issues with public transport.
- **Theme 2: Traffic and parking.**
- **Theme 3: Anxiety and stress.**
- **Theme 4: Challenges during the journey.**
 - Limited mobility.
 - Difficulty being in vehicles.
 - Lack of accessible facilities.
 - Neurological condition symptoms.
 - Weather conditions.
- **Theme 5: Travel distance and costs.**
- **Theme 6: Difficult to plan the travel.**
 - Difficulty in arranging transport.
 - Need to rely on friends or family.
 - Need to rely on hospital transport.
 - Difficult to find chaperone.
 - Spending long time away.
 - Having to take time off.
- **Theme 7: At the hospital.**
 - Navigating in the hospital.
 - Waiting for appointment.
- **Theme 8: Difficulty getting appointments.**

Theme 1: Public transport.

Respondents have to rely on public transport to attend their appointments. However there are several challenges related to public transport that cause difficulty for them.

Public transport not reliable or non-existent.

"Travel by train when they strike all the time..."

"There is no train or bus service"

"Public transport is not reliable with buses regularly being late or cancelled and only running hourly. "

No direct public transport/multiple changes.

"Have to use a variety of public transport to get there - car, train, and tube or bus."

"Have to get 4 buses"

Accessibility issue with public transport.

"I find public transport hard to navigate now as I struggle more and more with walking and my balance"

" transferring between busses as a wheelchair user is stressful especially if there isn't a space"

Theme 2: Traffic and parking.

Another source of difficulty is navigating through the traffic and finding parking spaces.

"Difficult to follow the traffic speed"

"Access to hospitals and parking is a nightmare."

"if clinics are in afternoons, it makes it harder to find a close enough parking space"

"The journey causes anxiety if traffic is bad and parking can be difficult at the hospital"

Theme 3: Anxiety and stress.

Dealing with the uncertainties and challenges of travelling for appointments on top of having neurological conditions also induce anxiety and stress.

"I travel with patient transport services but it affects my mental health and anxiety and I could never make my own way I panic"

"Stress due to being out of the house, waiting, standing in a queue, speaking to people such as receptionist, Dr or nurse almost always ends up with me in full spasm...Stress causes me to be unbalanced and forget how to move, walk, stand."

"I worry I will have issues that stop me from traveling, i.e. headaches."

"...getting to the appointments is more stressful than the actual appointment"

" Stress of travelling to London. Worry about train cancellations /missing appointment."

Theme 4: Challenges during the journey.

There are multiple challenges during the journey to appointments due to respondents' neurological conditions.

Limited mobility.

"I have difficulty getting out from the house to the car & vice versa at the hospital at the other end of the journey."

"My mobility is affected so I need help"

Difficulty being in vehicles.

"I have to lie in car and I feel very bad after that"

"Simply sitting up is difficult for me to do for long periods. By the time I arrive at an appointment I'm already exhausted and struggling."

"I have pain in my back if I have to sit in the car for too long"

"Being upright with a CSF Leak is monstrously painful and to have to be upright for moments is tough.... There needs to be more awareness and support / resources for us Leakers"

"...undoing any treatments they could do by traveling back"

Lack of accessible facilities.

"Accessing buildings in my wheelchair."

"Parking is an issue. Hospital with outdoor paths which are narrow and difficult to use as a wheelchair user especially if pedestrians on them. Waiting rooms cramped...no available space to put wheelchair in. Not all hospitals seem to have changing places bathroom and some have small disabled toilets with little room for standing pivot transfer with carer."

"Usually no suitable toileting facilities available. Had to remove power pack from wheelchair as emas ambulance strapping system couldn't fit around it."

Neurological condition symptoms (e.g., pain and fatigue).

"I find it very difficult because of my balance and fatigue"

"Memory problem"

"Ataxia caused by MS causes extreme motion sickness"

"Pain with sitting lasting days afterwards, nausea making me likely to vomit"

Weather conditions

"I usually use my mobility scooter but if the weather is bad I have to use a Taxi."

"The temperature of the day has an impact on my world so often there are challenges"

"Impossible to get to in harsh winter weather as over moorland."

Theme 5: Travel distance and costs

Another main theme that emerged was long- travel distance and high costs associated with travelling for appointments.

"I have to travel to London from Suffolk for my neurogenetic appointments - this means a very long convoluted journey via buses, trains, taxis"

"I need to drive for 2.5 hours"

"whilst I drive, the nearest specialist is 30 miles away"

"Going by taxi is costly at £13 to £15 each way."

"I've taken a few taxis this past month and it's cost me over £200. I have completed a form to get reimbursed by esa department but haven't heard anything. I went over my overdraft, couldn't buy food and direct debits didn't get paid."

Theme 6: Difficult to plan the travel.

It was also difficult for respondents to plan their travel to the appointments.

Difficulty in arranging transport.

"Transport isn't easily available and has to be booked 3 weeks in advance."

"Have to plan it in advance, book train tickets online."

Need to rely on friends or family.

"My driving licence was revoked for medical reasons. I rely on partner to drive me"

"I am no longer able to drive, cannot go out on my own, so have to arrange for a companion and ask family members to take me in the car"

Need to rely on hospital transport.

"I can only go by hospital transport, which can take the entire day"

"Because I need to use hospital transport. I use a powered wheelchair and there are no taxis where I live that will take the chair. Hospital transport is not always available so appointments have to be rescheduled."

Difficult to find chaperone.

"I cannot go outside without a chaperone and I live alone since my husband died suddenly."

"I cannot use public transport and have no friends or family to take me. Currently pay for carer to take me which is expensive"

Spending long time away from home

"I have to use patient transport and have to be ready for pickup 4 hours before appointment time and return journey can only be booked once appointment concluded and have to again wait up to 4 hours for pickup to travel home. Just finished 30 sessions of treatment and each day was between 8-13 hours for 20 minutes of treatment."

"Arranging transport to suit appointment times and being away for most of the day"

Having to take time off

"I have to travel by train and it is a 90 minute journey each way, so I have to take a while day off work to get to an appointment that might only be 10 minutes long"

"I have to take 2 days off work 1 for appointment then another to get over the travelling"

Theme 7: At the hospital

Navigating the hospital

"Navigating around hospital site. Physio and fracture/trauma units are far from the carpark"

"Finding way there"

"parking and walking to the consult area."

Waiting for appointment

"discomfort travelling + waiting in out patient departments."

"I don't like the busy areas and clinic waiting areas"

Theme 8: Difficulty getting appointments

Some respondents do not have appointments themselves or are waiting to be allocated one.

"I am permanently housebound and no appointments except gp because of this"

"I don't have any appointments, I've not been seen by a neurologist since my diagnosis and only once has a GP mentioned it"

Meeting with specialists.

Purpose of seeing or speaking to a specialist.

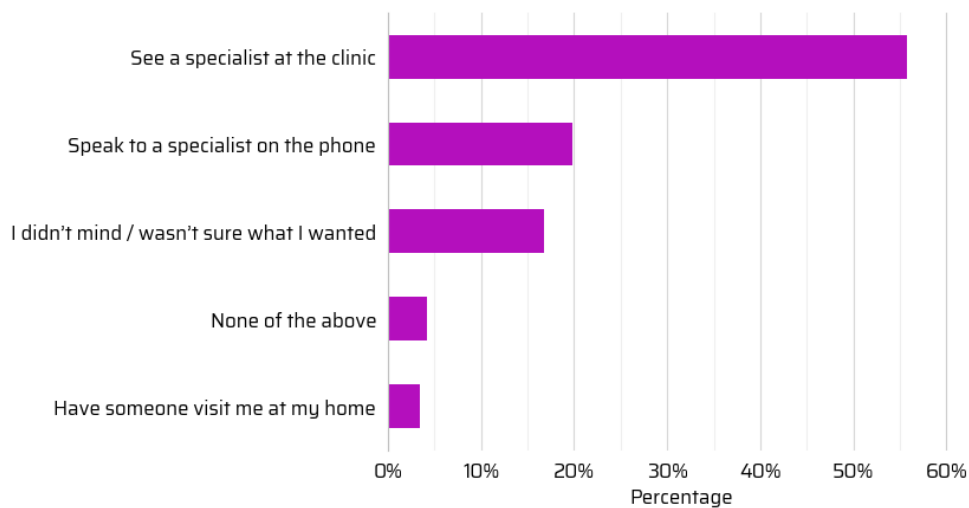


Figure 19: Purpose of seeing or speaking to a specialist.

Table 18: Purpose of seeing or speaking to a specialist.

Intention	Respondents	Percentage
See a specialist at the clinic	416	55.76
Speak to a specialist on the phone	148	19.84
I didn't mind / wasn't sure what I wanted	125	16.76
None of the above	31	4.16
Have someone visit me at my home	26	3.49

Able to meet/speak to a specialist.

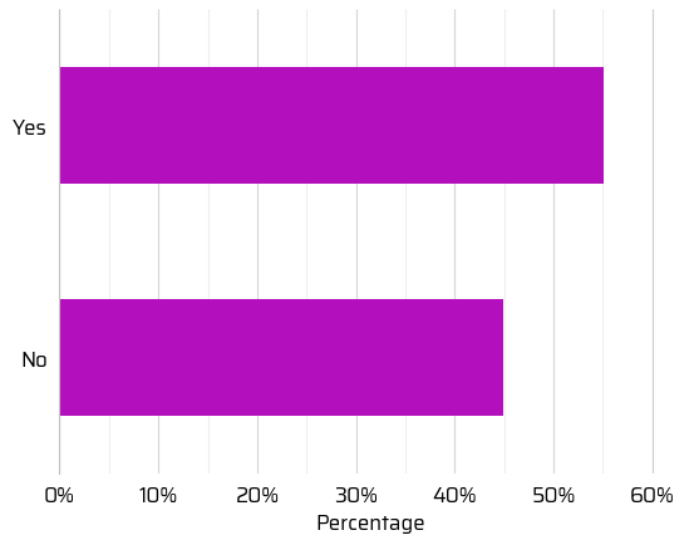


Figure 20.: Whether respondents were able to meet or speak to a specialist.

Table 19: Whether respondents were able to meet or speak to a specialist.

Appointments	Respondents	Percentage
Yes	412	55.08
No	336	44.92

Convenience of meeting a specialist.

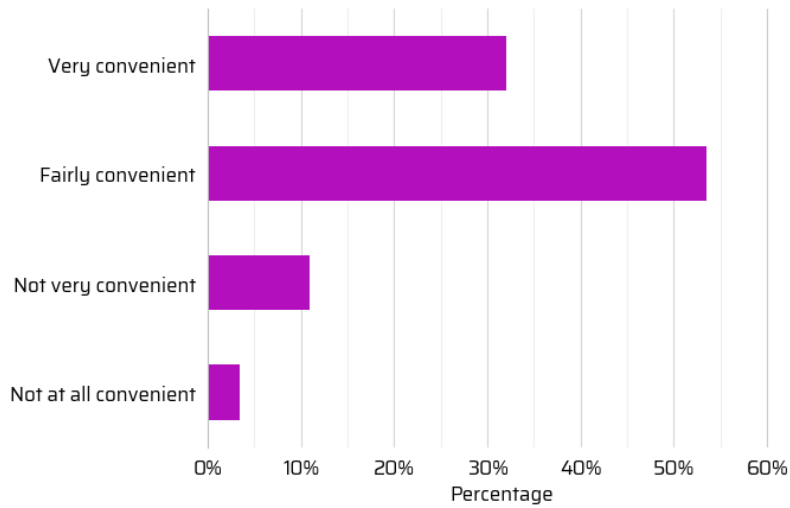


Figure 21: Convenience of meeting a specialist.

Table 20: Convenience of meeting a specialist.

Convenience	Respondents	Percentage
Very convenient	131	32.03
Fairly convenient	219	53.55
Not very convenient	45	11.0
Not at all convenient	14	3.42

Reasons for not getting an appointment or a convenient one.

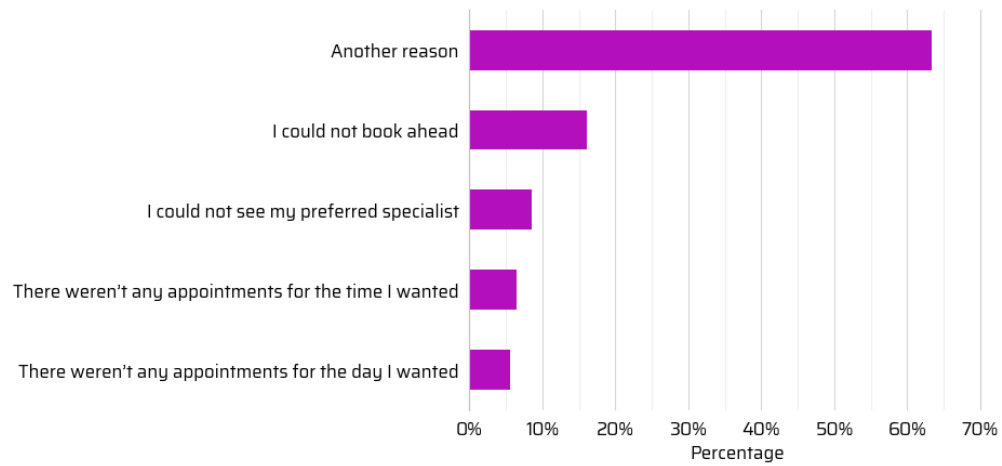


Figure 22: Reasons for not getting an appointment or a convenient one.

Table 21: Reasons for not getting an appointment or a convenient one.

Reason	Respondents	Percentage
Another reason	461	63.32
I could not book ahead	117	16.07
I could not see my preferred specialist	62	8.52
There weren't any appointments for the time I wanted	47	6.46
There weren't any appointments for the day I wanted	41	5.63

Reasons why appointments could not be made or a convenient one offered.

Word cloud



Figure 23: Reasons why appointments could not be made or a convenient one offered.

Thematic analysis

A thematic analysis was conducted for responses to the question. The following reasons were found on why the respondents could not get an appointment:

- Long waiting list/still waiting.
- No specialist or appointment for my condition available.
- No need for appointment/did not ask for one.
- No follow-up.
- Not offered one or refused to be referred.
- Not qualified for one.
- Taken off from waiting list.
- Appointment cancelled.

- Could not attend due to logistical or mobility-related problems.
- Could not attend due to work commitments.
- Referred to a different hospital or another appointment.
- Gave up on getting one.
- COVID restriction.
- Not sure how to get one.
- Offered alternative form of appointment (phone, online, email).
- Convoluted appointment system.
- Admin errors.
- Managed to get an appointment.

Long waiting list/still waiting.

"Placed on 12 month waiting list"

"2 year wait so paid private"

No specialist or appointment for my condition available

"No consultants available"

"I was offered an appointment, but my specialist didn't turn up"

"There aren't any specialists in my condition."

No need for appointment/did not ask for one

"I haven't needed to recently."

"I didnt ask for appointment."

No follow-up

"I was awaiting a phone call from my designated contact nurse but she didn't ring back until the following week"

"Can't get in touch with the team. I seem to have been sent into a black hole"

Not offered one or refused to be referred

"They refused my referral"

"My GP would not refer me."

Not qualified for one

"I have no health insurance and cannot qualify for specialist indigent care. I have no specialist help"

Taken off from waiting list

"My name has been taken off the neurological waiting list due to a backlog for patients"

Appointment cancelled

"My original appointment was cancelled at short notice due to junior doctor strike action, the one offered in replacement I could not take due to holiday commitments the next one offered was 6months later"

"Two previous appointments had been cancelled"

Could not attend due to logistical or mobility-related problems

"Being covered in extreme multiple injuries makes travelling and being dressed impossible on many of my days."

"It's far away and not easy to get to"

Could not attend due to work commitments

"work commitments"

"...need to go into work."

Referred to a different hospital or another appointment

"I have been referred to a different hospital/pain management clinic"

"I rang my neurologist's secretary after receiving a letter, cancelling my botox treatment appt and pushing that appt back 3 months. She explained that this was due to accommodating staff holidays. The secretary very kindly rang me a couple of weeks later, to offer me an ad hoc appointment, one month later than my original appt. Although grateful for this, it was deeply upsetting and distressing to receive that extremely lengthy appt delay."

Gave up on getting one

"I given up"

"its felt nothing more can be done"

COVID restriction

"They wrote to say Covid 19 has caused massive delay, still waiting for first appointment to pain relief options for Trigeminal Neuralgia"

"Covid restrictions"

Not sure how to get one

"I don't know who or where to ask."

"Since COVID I have had no follow up appointments. It's difficult to no where to start again"

Offered alternative form of appointment (phone, online, email)

"Phone appointment"

"My Neurologist is overloaded and I email his secretary & he emails or writes back"

"I wanted to see a specialist in person, but only had a telephone appointment. As I struggle with speech sometimes, this makes it hard to communicate"

Convolutd appointment system

"I am being bounced back and forth from Neurology to Neurosurgery with no one taking responsibility for my care."

"I am now on the PIFU scheme, phoned for appointment. System very difficult to get an appointment and involved a long wait. System not ideal for somebody who finds phone use difficult."

Admin errors

"He rang at a totally different time of day than the agreed appointment which should have been 4 pm and he rang at 10am"

Managed to get an appointment

"I had been to an appointment"

"I did get an appointment at a convenient time"

Action taken following not getting an appointment or not offered a convenient one.

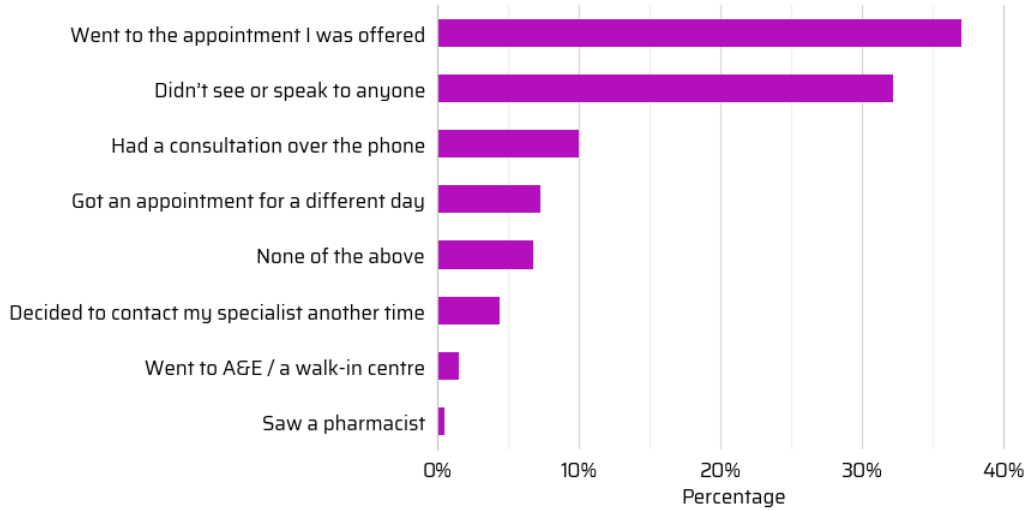


Figure 24: Action taken following not getting an appointment or not offered a convenient one.

Table 22: Action taken following not getting an appointment or not offered a convenient one.

Action	Respondents	Percentage
Went to the appointment I was offered	277	37.03
Didn't see or speak to anyone	241	32.22
Had a consultation over the phone	75	10.03
Got an appointment for a different day	55	7.35
None of the above	51	6.82
Decided to contact my specialist another time	33	4.41
Went to A&E / a walk-in centre	12	1.6
Saw a pharmacist	4	0.53

Medical appointments

Access to medical appointments in the last eight weeks.

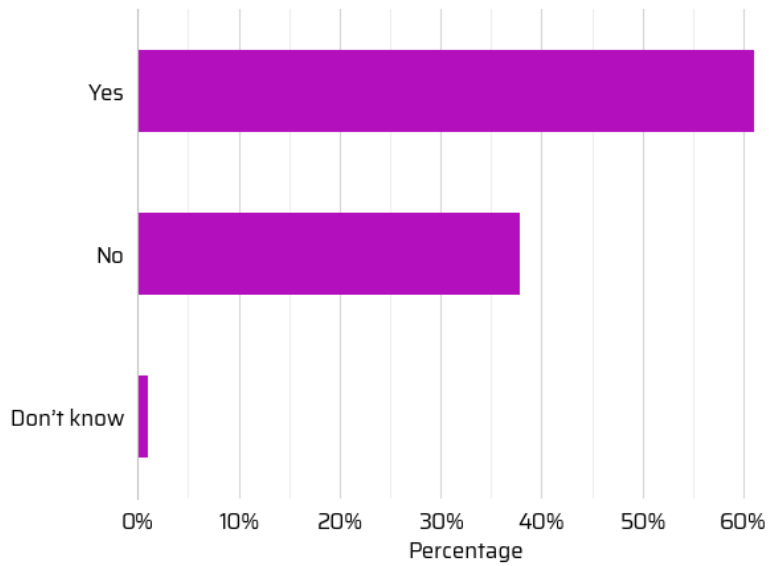


Figure 25: Access to medical appointments in the last eight weeks.

Table 23: Access to medical appointments in the last eight weeks.

Appointments	Respondents	Percentage
Yes	457	61.1
No	283	37.83
Don't know	8	1.07

Number of medical appointments

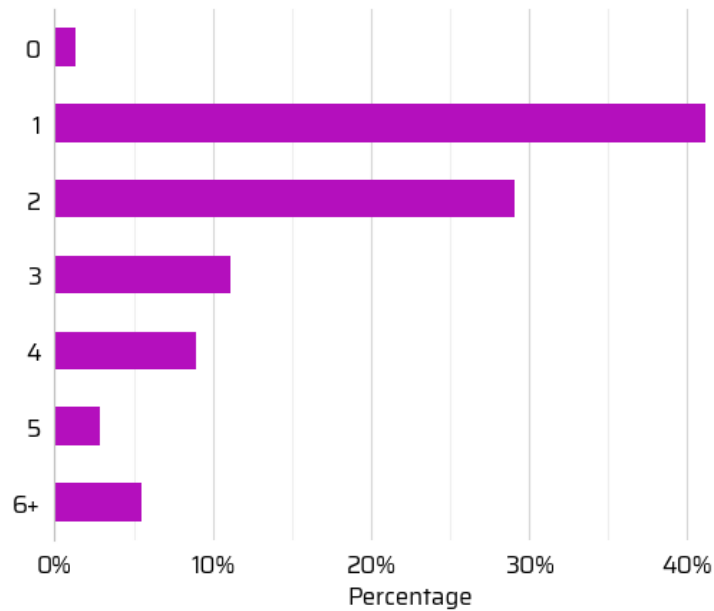


Figure 26: Number of medical appointments.

Table 24: Number of medical appointments.

Number of appointments	Respondents	Percentage
0	6	1.31
1	188	41.14
2	133	29.1
3	51	11.16
4	41	8.97
5	13	2.84
6+	25	5.47

Helpfulness of medical appointments

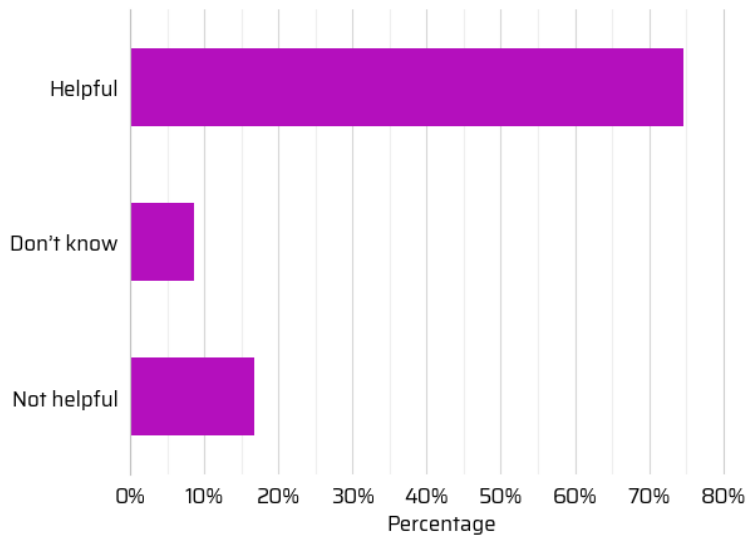


Figure 27: Helpfulness of medical appointments held in the last eight weeks.

Table 25: Helpfulness of medical appointments held in the last eight weeks.

Helpfulness	Respondents	Percentage
Helpful	766	74.66
Don't know	88	8.58
Not helpful	172	16.76

Specialty of medical appointments.

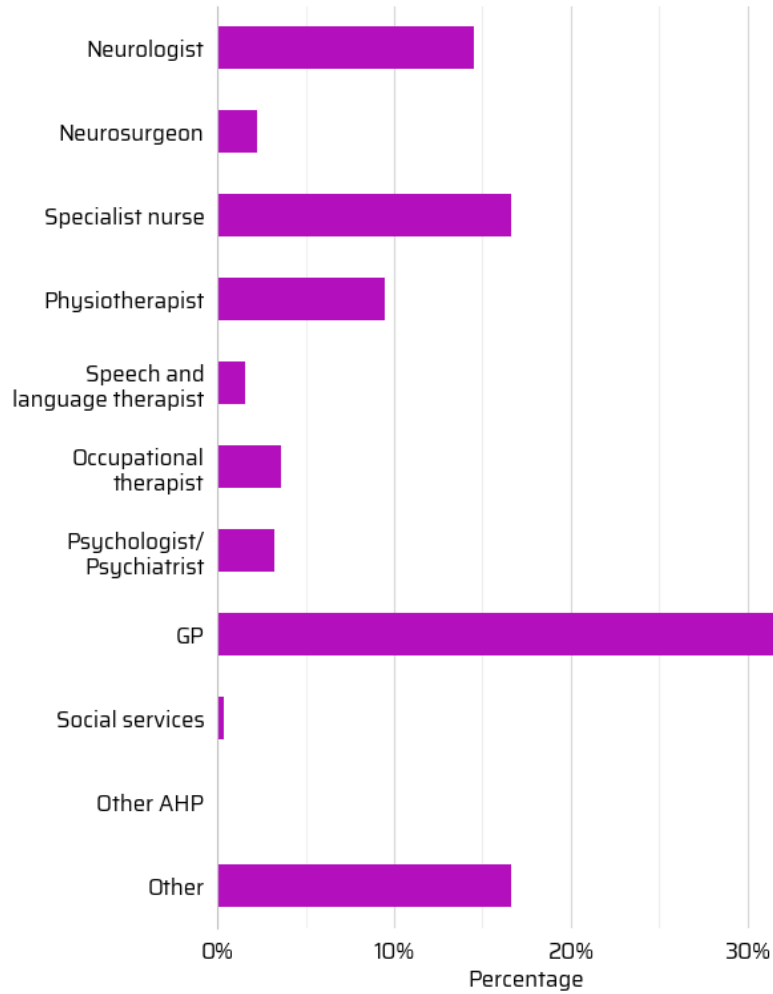


Figure 28: Speciality of the medical appointments held in the last eight weeks.

Table 26: Speciality of the medical appointments held in the last eight weeks.

Specialty	Respondents	Percentage
Neurologist	130	14.53
Neurosurgeon	20	2.23
Specialist nurse	149	16.65
Physiotherapist	85	9.5
Speech and language therapist	14	1.56
Occupational therapist	32	3.58
Psychologist/Psychiatrist	29	3.24

GP	284	31.73
Social services	3	0.34
Other AHP	0	0.0
Other	149	16.65

Mode of medical appointments completed.

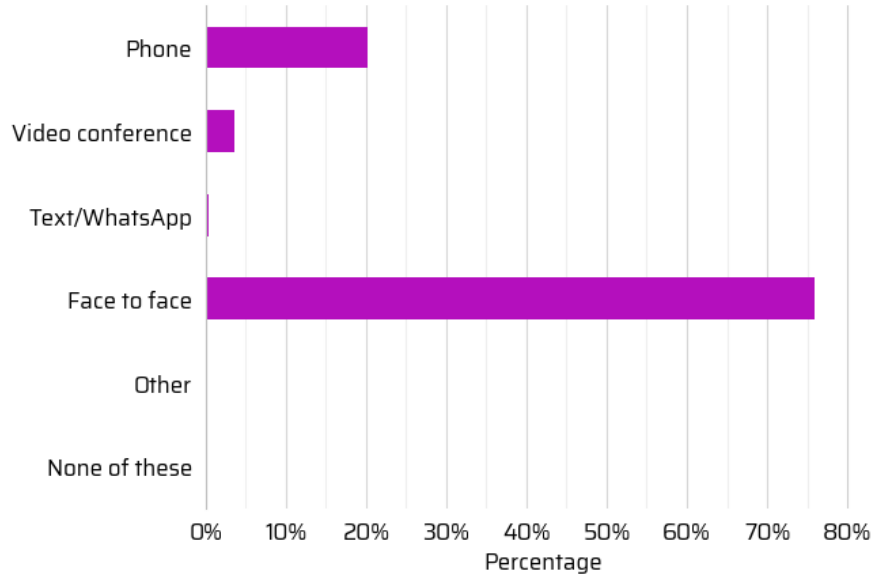


Figure 29: Mode of medical appointments completed in the last eight weeks.

Table 27: Mode of medical appointments completed in the last eight weeks.

Mode	Respondents	Percentage
Phone	201	20.14
Video conference	36	3.61
Text/WhatsApp	4	0.4
Face to face	757	75.85
Other	0	0.0
None of these	0	0.0

Mental health

Current feelings.

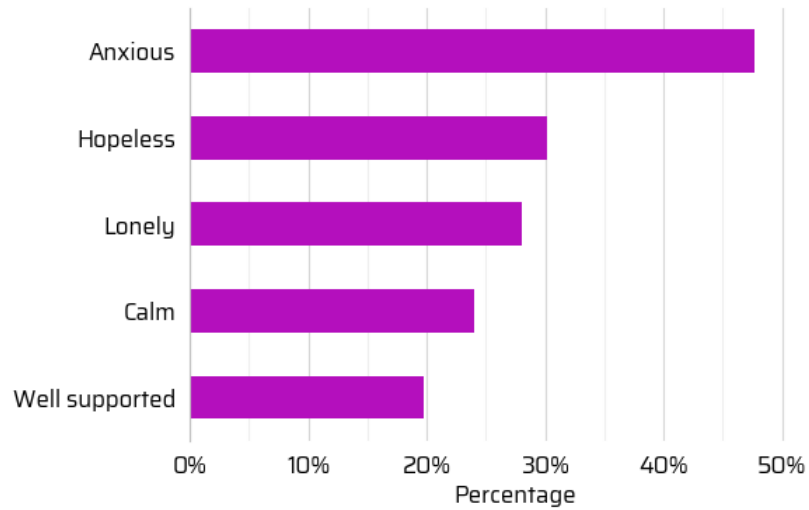


Figure 30: Feelings of the respondents at the time of the survey.

Table 28: Feelings of the respondents at the time of the survey.

Feelings	Respondents	Percentage
Anxious	357	47.73
Hopeless	226	30.21
Lonely	210	28.07
Calm	180	24.06
Well supported	148	19.79

Extent mental health needs are met.

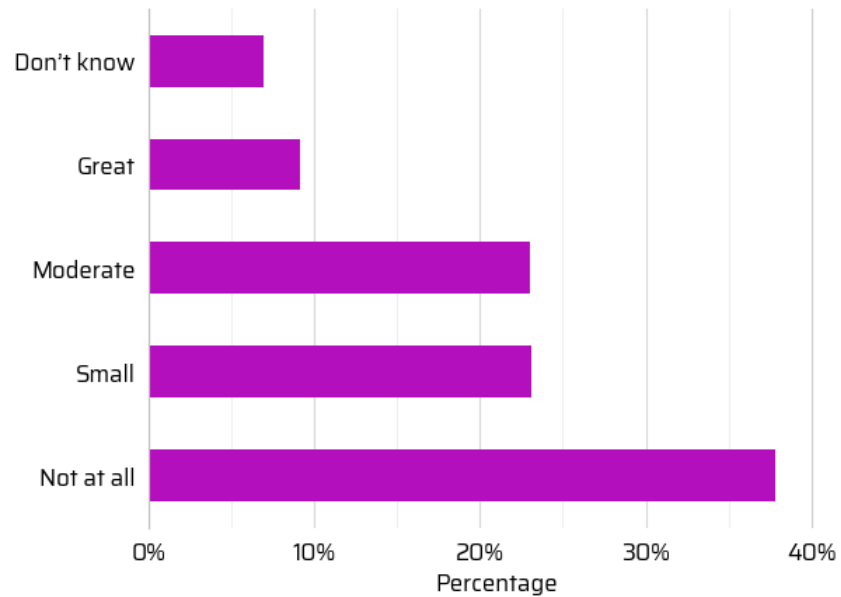


Figure 31: Extent respondents reported their mental health needs were being met.

Table 29: Extent respondents reported their mental health needs were being met.

Needs met	Respondents	Percentage
Don't know	52	6.95
Great	68	9.09
Moderate	172	22.99
Small	173	23.13
Not at all	283	37.83

Extent mental health needs are met by whether diagnosed with multiple neurological conditions.

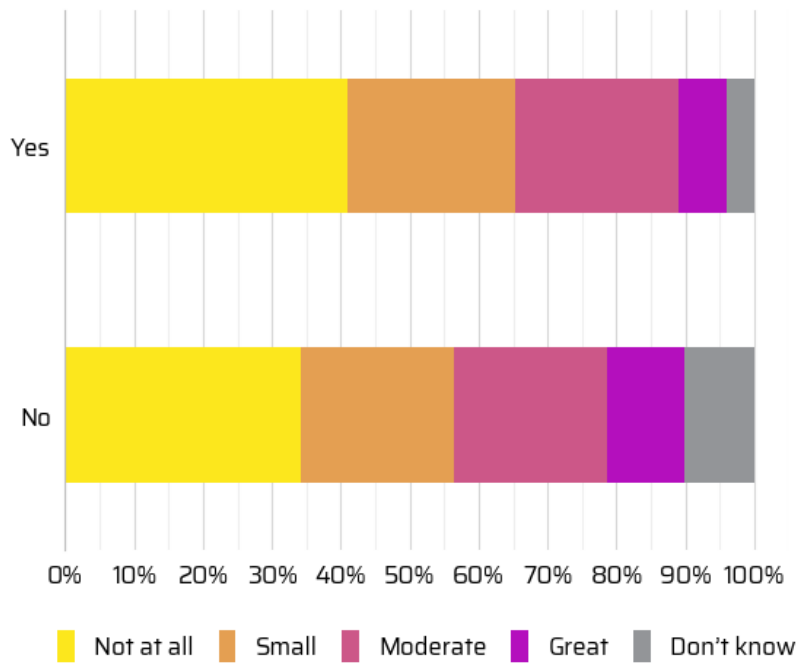


Figure 32: Extent mental health needs are met by whether diagnosed with multiple neurological conditions.

Table 30: Extent mental health needs are met by whether diagnosed with multiple neurological conditions.

Multiple neurological conditions	Needs met	Respondents	Percentage
Yes	Don't know	15	4.0
	Great	26	6.93
	Moderate	89	23.73
	Small	91	24.27
	Not at all	154	41.07
No	Don't know	37	10.03
	Great	42	11.38
	Moderate	82	22.22
	Small	82	22.22

Not at all

126

34.15

Extent mental health needs are met by age groups.

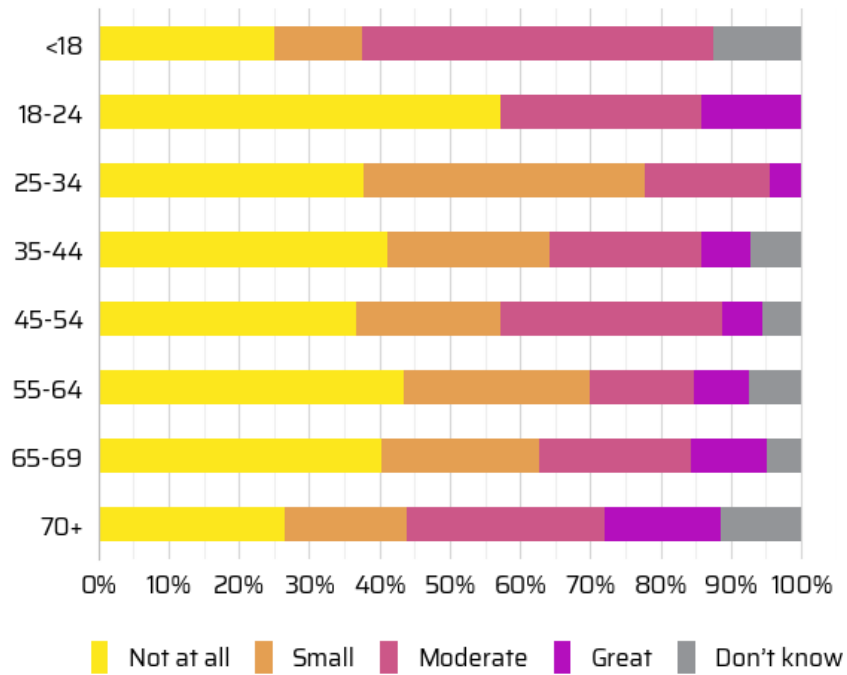


Figure 33: Extent mental health needs are met by age groups.

Table 31: Extent mental health needs are met by age groups.

Age	Needs met	Respondents	Percentage
<18	Don't know	1	12.5
	Great	0	0.0
	Moderate	4	50.0
	Small	1	12.5
	Not at all	2	25.0
18-24	Don't know	0	0.0
	Great	1	14.29
	Moderate	2	28.57
	Small	0	0.0

	Not at all	4	57.14
	Don't know	0	0.0
	Great	2	4.44
25-34	Moderate	8	17.78
	Small	18	40.0
	Not at all	17	37.78
	Don't know	4	7.14
	Great	4	7.14
35-44	Moderate	12	21.43
	Small	13	23.21
	Not at all	23	41.07
	Don't know	9	5.59
	Great	9	5.59
45-54	Moderate	51	31.68
	Small	33	20.5
	Not at all	59	36.65
	Don't know	17	7.39
	Great	18	7.83
55-64	Moderate	34	14.78
	Small	61	26.52
	Not at all	100	43.48
	Don't know	5	4.9
	Great	11	10.78
65-69	Moderate	22	21.57
	Small	23	22.55
	Not at all	41	40.2
	Don't know	16	11.51
70+	Great	23	16.55

Moderate	39	28.06
Small	24	17.27
Not at all	37	26.62

Extent mental health needs are met by gender.

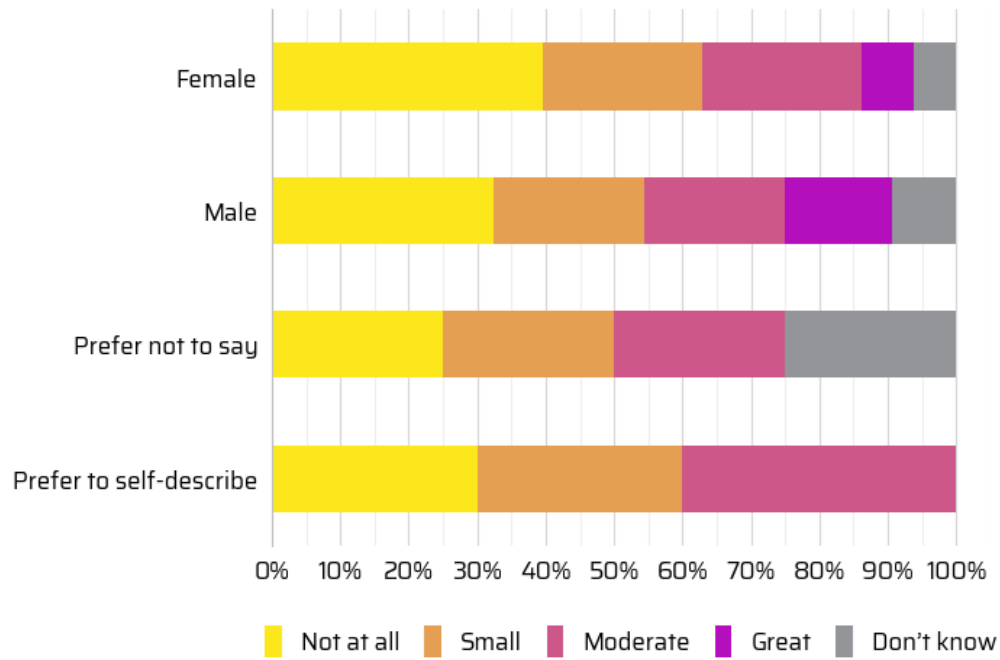


Figure 34: Extent mental health needs are met by gender.

Table 32: Extent mental health needs are met by gender.

Gender	Needs met	Respondents	Percentage
Female	Don't know	36	6.27
	Great	43	7.49
	Moderate	134	23.34
	Small	134	23.34
	Not at all	227	39.55
Male	Don't know	15	9.38
	Great	25	15.62
	Moderate	33	20.62

	Small	35	21.88
	Not at all	52	32.5
	Don't know	1	25.0
	Great	0	0.0
Prefer not to say	Moderate	1	25.0
	Small	1	25.0
	Not at all	1	25.0
	Don't know	0	0.0
	Great	0	0.0
Prefer to self-describe	Moderate	4	40.0
	Small	3	30.0
	Not at all	3	30.0

Extent mental health needs are met by employment status.

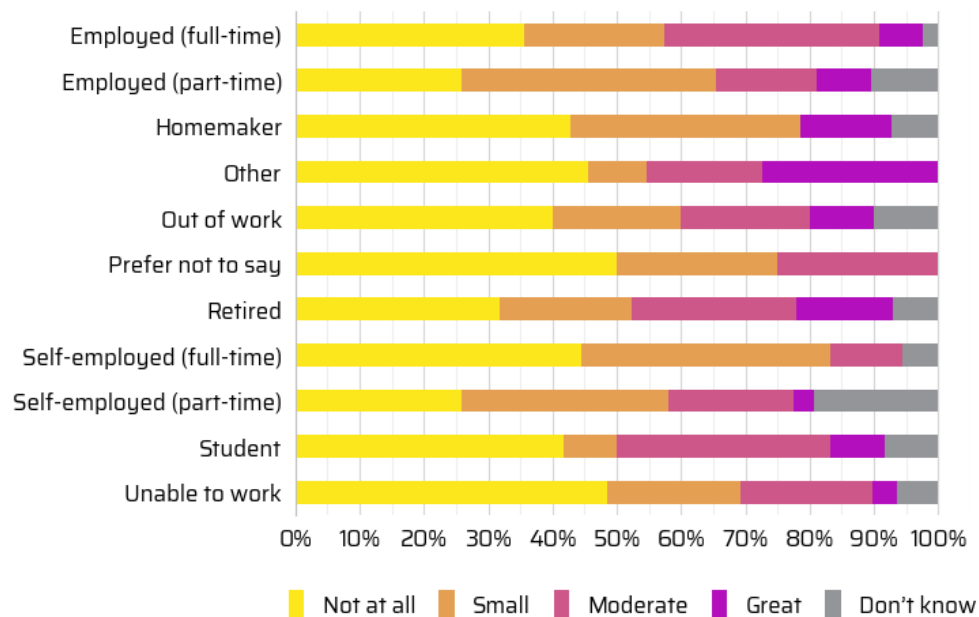


Figure 35: Extent mental health needs are met by employment status.

Table 33: Extent mental health needs are met by employment status.

Employment status	Needs met	Respondents	Percentage
Employed (full-time)	Don't know	2	2.3
	Great	6	6.9
	Moderate	29	33.33
	Small	19	21.84
	Not at all	31	35.63
Employed (part-time)	Don't know	6	10.34
	Great	5	8.62
	Moderate	9	15.52
	Small	23	39.66
	Not at all	15	25.86
Homemaker	Don't know	1	7.14
	Great	2	14.29
	Moderate	0	0.0
	Small	5	35.71
	Not at all	6	42.86
Other	Don't know	0	0.0
	Great	3	27.27
	Moderate	2	18.18
	Small	1	9.09
	Not at all	5	45.45
Out of work	Don't know	1	10.0
	Great	1	10.0
	Moderate	2	20.0
	Small	2	20.0
	Not at all	4	40.0

	Don't know	0	0.0
	Great	0	0.0
Prefer not to say	Moderate	1	25.0
	Small	1	25.0
	Not at all	2	50.0
	Don't know	19	7.09
	Great	40	14.93
Retired	Moderate	69	25.75
	Small	55	20.52
	Not at all	85	31.72
	Don't know	1	5.56
	Great	0	0.0
Self-employed (full-time)	Moderate	2	11.11
	Small	7	38.89
	Not at all	8	44.44
	Don't know	6	19.35
	Great	1	3.23
Self-employed (part-time)	Moderate	6	19.35
	Small	10	32.26
	Not at all	8	25.81
	Don't know	1	8.33
	Great	1	8.33
Student	Moderate	4	33.33
	Small	1	8.33
	Not at all	5	41.67
	Don't know	15	6.38
Unable to work	Great	9	3.83
	Moderate	48	20.43

Small	49	20.85
Not at all	114	48.51

Extent mental health needs are met by number of dependents.

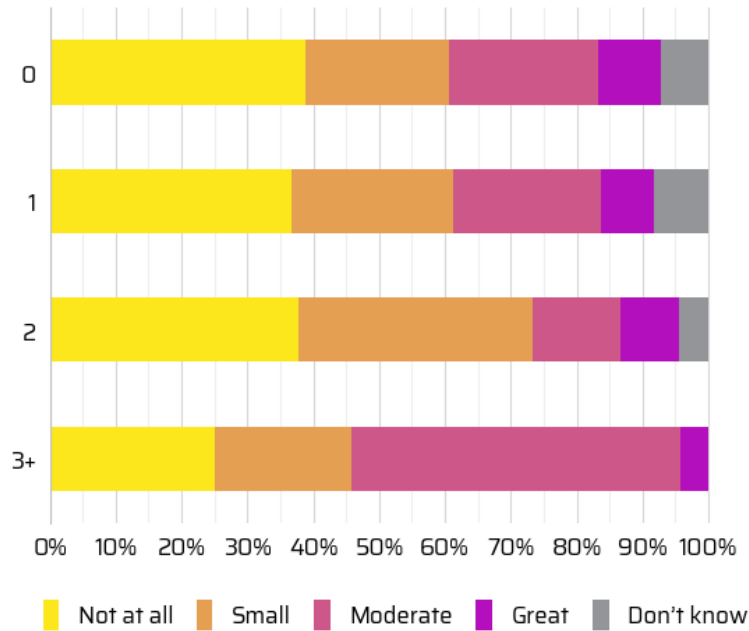


Figure 36: Extent mental health needs are met by number of dependents.

Table 34: Extent mental health needs are met by number of dependents.

Number of dependents	Needs met	Respondents	Percentage
0	Don't know	38	7.14
	Great	51	9.59
	Moderate	121	22.74
	Small	116	21.8
	Not at all	206	38.72
1	Don't know	12	8.16
	Great	12	8.16

	Moderate	33	22.45
	Small	36	24.49
	Not at all	54	36.73
	Don't know	2	4.44
	Great	4	8.89
2	Moderate	6	13.33
	Small	16	35.56
	Not at all	17	37.78
	Don't know	0	0.0
	Great	1	4.17
3+	Moderate	12	50.0
	Small	5	20.83
	Not at all	6	25.0

Frequency NHS A&E/emergency services were sought.

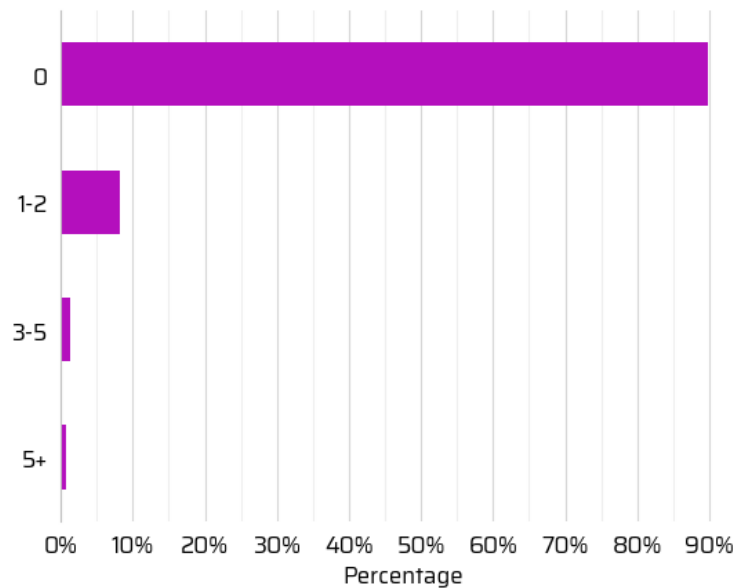


Figure 37: Frequency that NHS A&E/emergency services were sought in the last eight weeks.

Table 35: Frequency that NHS A&E/emergency services were sought in the last eight weeks.

Frequency	Respondents	Percentage
0	672	89.84
1-2	61	8.16
3-5	10	1.34
5+	5	0.67

Frequency NHS A&E/emergency services were sought by whether diagnosed with multiple neurological conditions.

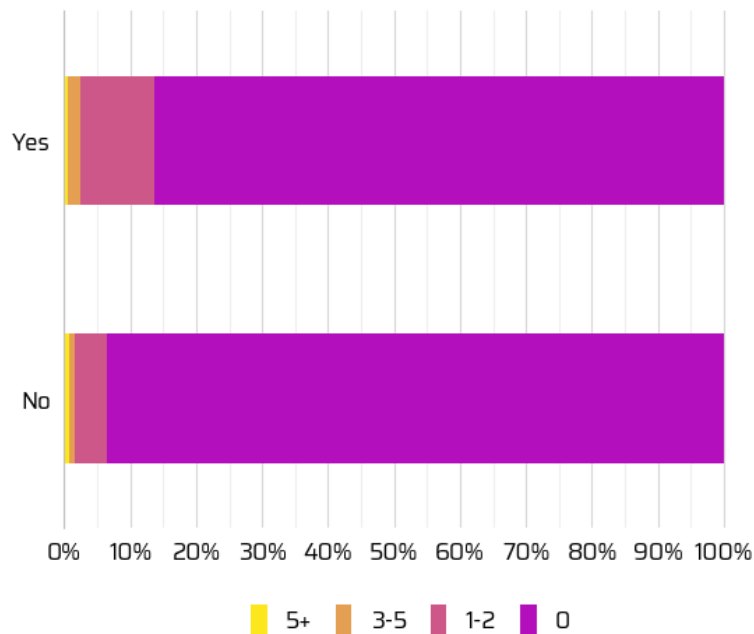


Figure 38: Frequency NHS A&E/emergency services were sought by whether diagnosed with multiple neurological conditions.

Table 36: Frequency NHS A&E/emergency services were sought by whether diagnosed with multiple neurological conditions.

Multiple neurological conditions	Frequency	Respondents	Percentage
Yes	0	324	86.4
	1-2	42	11.2

	3-5	7	1.87
	5+	2	0.53
No	0	345	93.5
	1-2	18	4.88
	3-5	3	0.81
	5+	3	0.81

Frequency NHS A&E/emergency services were sought by age group.

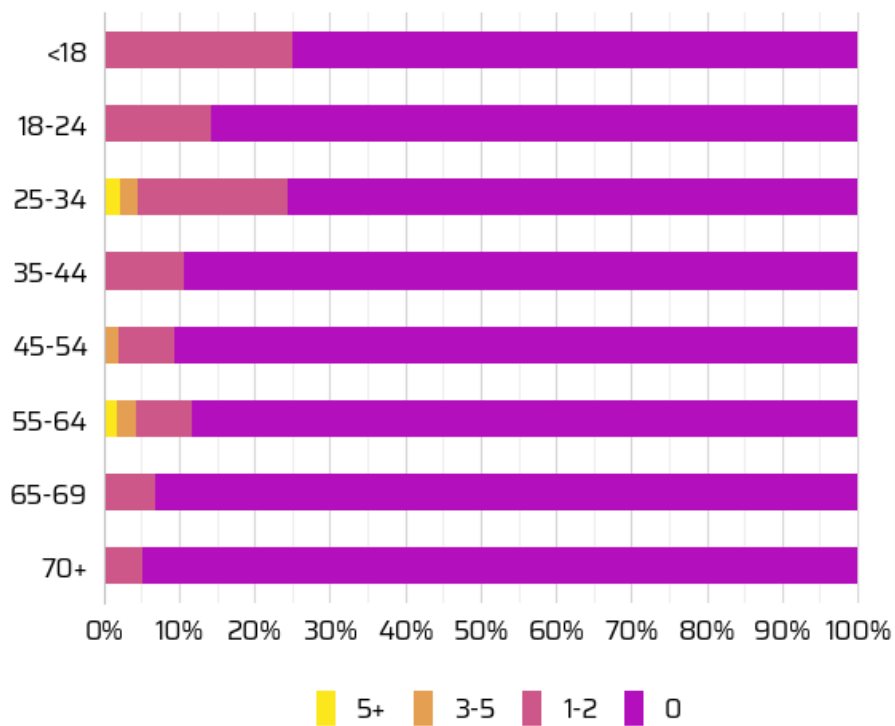


Figure 39: Frequency NHS A&E/emergency services were sought by age group.

Table 37: Frequency NHS A&E/emergency services were sought by age group.

Age	Frequency	Respondents	Percentage
<18	0	6	75.0
	1-2	2	25.0
	3-5	0	0.0
	5+	0	0.0

18-24	0	6	85.71
	1-2	1	14.29
	3-5	0	0.0
	5+	0	0.0
25-34	0	34	75.56
	1-2	9	20.0
	3-5	1	2.22
	5+	1	2.22
35-44	0	50	89.29
	1-2	6	10.71
	3-5	0	0.0
	5+	0	0.0
45-54	0	146	90.68
	1-2	12	7.45
	3-5	3	1.86
	5+	0	0.0
55-64	0	203	88.26
	1-2	17	7.39
	3-5	6	2.61
	5+	4	1.74
65-69	0	95	93.14
	1-2	7	6.86
	3-5	0	0.0
	5+	0	0.0
70+	0	132	94.96
	1-2	7	5.04
	3-5	0	0.0
	5+	0	0.0

Frequency NHS A&E/emergency services were sought by gender.

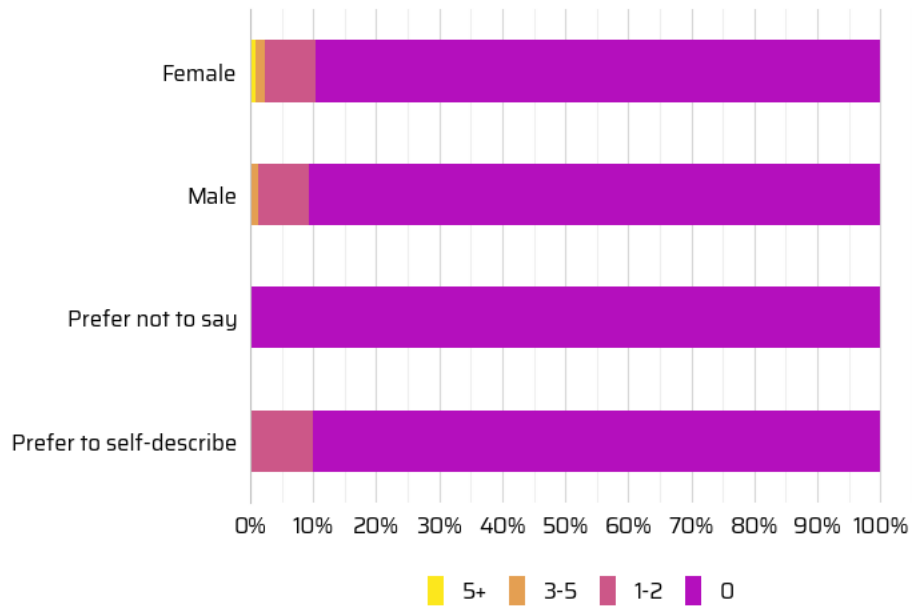


Figure 40: Frequency NHS A&E/emergency services were sought by gender.

Table 38: Frequency NHS A&E/emergency services were sought by gender.

Gender	Frequency	Respondents	Percentage
Female	0	514	89.55
	1-2	47	8.19
	3-5	8	1.39
	5+	5	0.87
Male	0	145	90.62
	1-2	13	8.12
	3-5	2	1.25
	5+	0	0.0
Prefer not to say	0	4	100.0
	1-2	0	0.0
	3-5	0	0.0
	5+	0	0.0

	0	9	90.0
Prefer to self-describe	1-2	1	10.0
	3-5	0	0.0
	5+	0	0.0

Frequency NHS A&E/emergency services were sought by employment status.

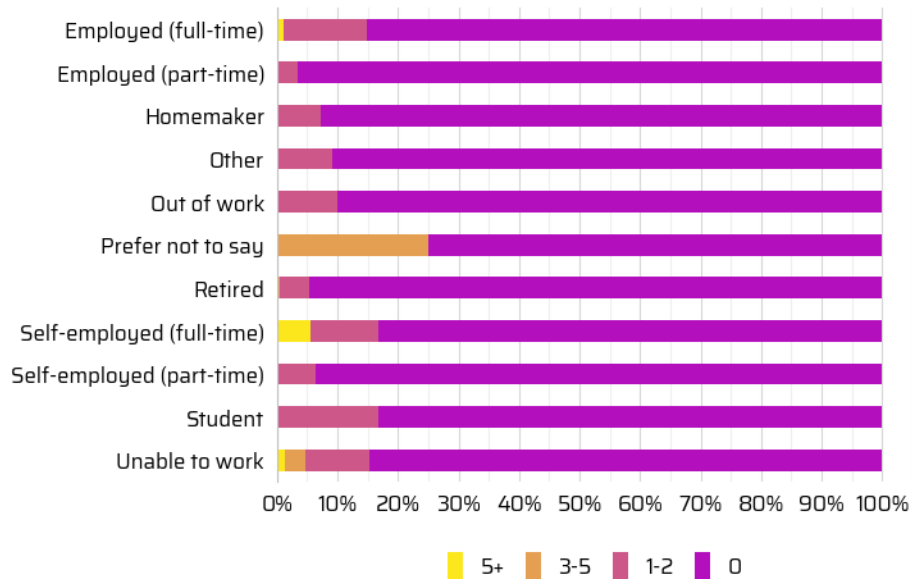


Figure 41: Frequency NHS A&E/emergency services were sought by employment status.

Table 39: Frequency NHS A&E/emergency services were sought by employment status.

Employment status	Frequency	Respondents	Percentage
Employed (full-time)	0	74	85.06
	1-2	12	13.79
	3-5	0	0.0
	5+	1	1.15
Employed (part-time)	0	56	96.55
	1-2	2	3.45
	3-5	0	0.0
	5+	0	0.0

Homemaker	0	13	92.86
	1-2	1	7.14
	3-5	0	0.0
	5+	0	0.0
Other	0	10	90.91
	1-2	1	9.09
	3-5	0	0.0
	5+	0	0.0
Out of work	0	9	90.0
	1-2	1	10.0
	3-5	0	0.0
	5+	0	0.0
Prefer not to say	0	3	75.0
	1-2	0	0.0
	3-5	1	25.0
	5+	0	0.0
Retired	0	254	94.78
	1-2	13	4.85
	3-5	1	0.37
	5+	0	0.0
Self-employed (full-time)	0	15	83.33
	1-2	2	11.11
	3-5	0	0.0
	5+	1	5.56
Self-employed (part-time)	0	29	93.55
	1-2	2	6.45
	3-5	0	0.0
	5+	0	0.0

Student	0	10	83.33
	1-2	2	16.67
	3-5	0	0.0
	5+	0	0.0
Unable to work	0	199	84.68
	1-2	25	10.64
	3-5	8	3.4
	5+	3	1.28

Frequency NHS A&E/emergency services were sought by number of dependents.

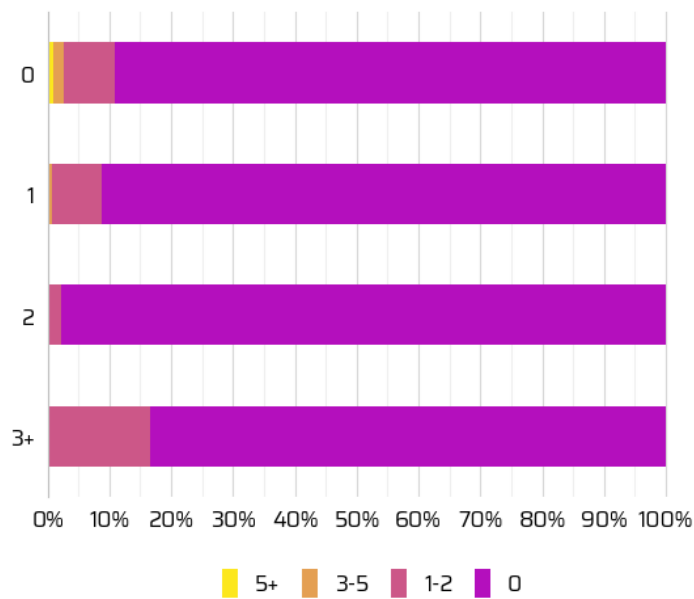


Figure 42: Frequency NHS A&E/emergency services were sought by number of dependents.

Table 40: Frequency NHS A&E/emergency services were sought by number of dependents.

Number of dependents	Frequency	Respondents	Percentage
0	0	474	89.1

	1-2	44	8.27
	3-5	9	1.69
	5+	5	0.94
1	0	134	91.16
	1-2	12	8.16
	3-5	1	0.68
	5+	0	0.0
2	0	44	97.78
	1-2	1	2.22
	3-5	0	0.0
	5+	0	0.0
3+	0	20	83.33
	1-2	4	16.67
	3-5	0	0.0
	5+	0	0.0

Overall experience of healthcare.

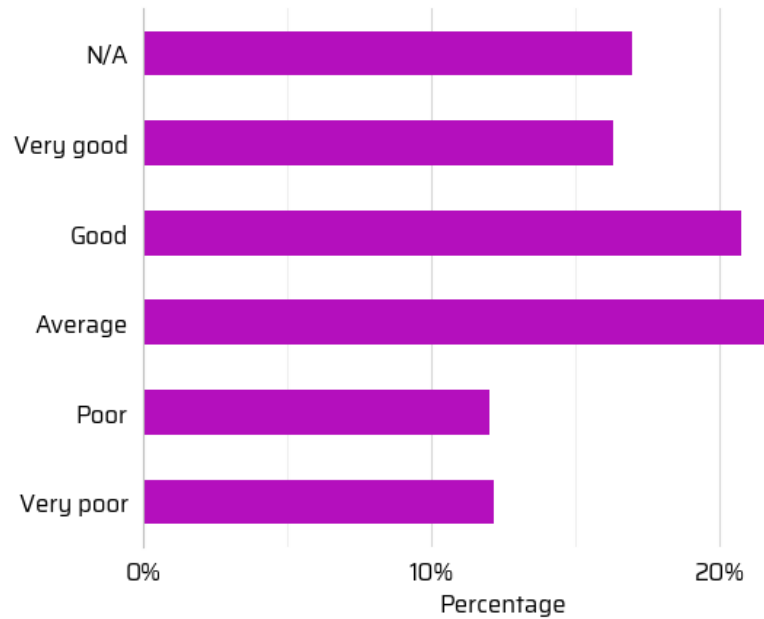


Figure 43: Overall experience of healthcare.

Table 41: Overall experience of healthcare.

Experience	Respondents	Percentage
N/A	127	16.98
Very good	122	16.31
Good	155	20.72
Average	163	21.79
Poor	90	12.03
Very poor	91	12.17

Overall experience of healthcare by whether diagnosed with multiple neurological conditions.

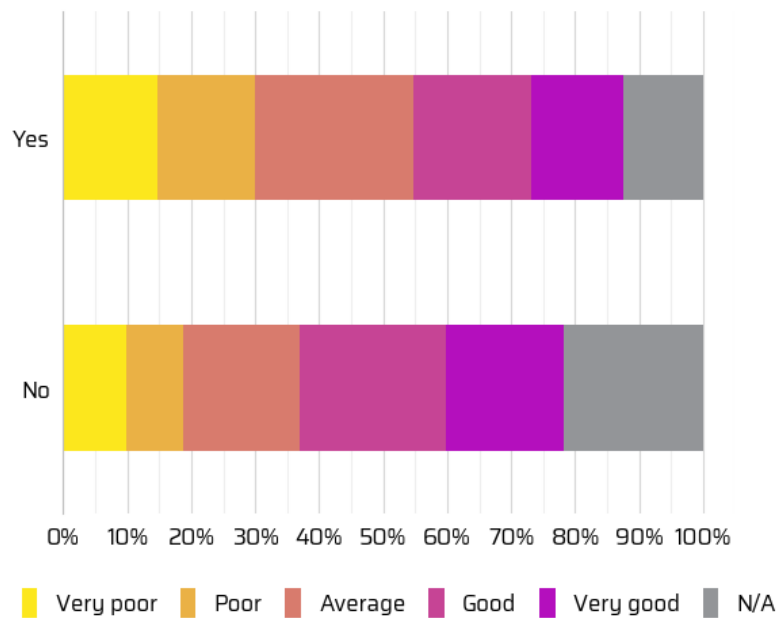


Figure 44: Overall experience of healthcare, broken down by whether diagnosed with multiple neurological conditions.

Table 42: Overall experience of healthcare, broken down by whether diagnosed with multiple neurological conditions.

Multiple neurological conditions	Experience	Respondents	Percentage
Yes	N/A	47	12.53
	Very good	54	14.4
	Good	69	18.4
	Average	93	24.8
	Poor	57	15.2
	Very poor	55	14.67
No	N/A	80	21.68
	Very good	68	18.43
	Good	85	23.04
	Average	67	18.16

Poor	33	8.94
Very poor	36	9.76

Overall experience of healthcare by age group.

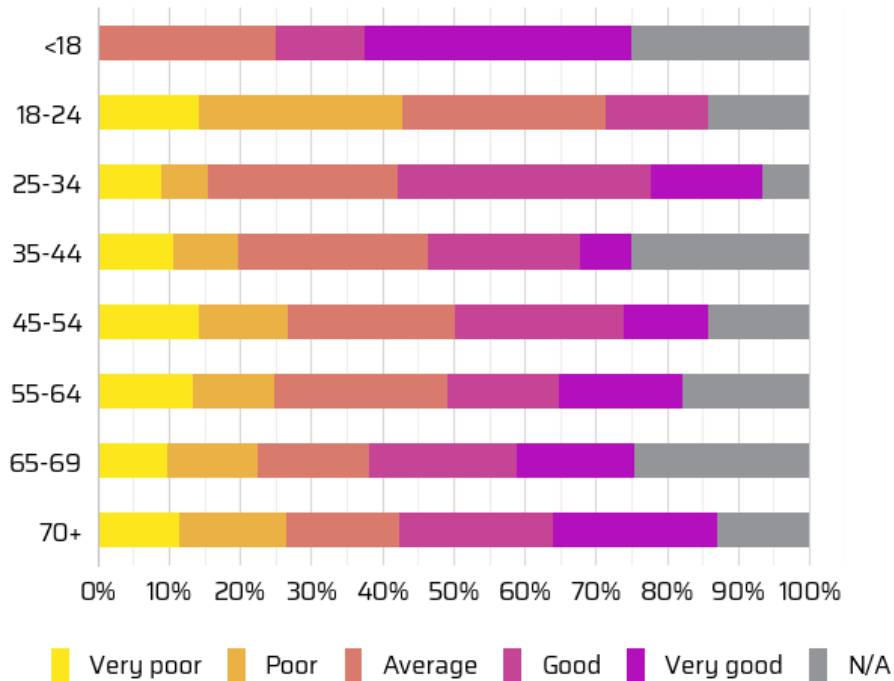


Figure 45: Overall experience of healthcare by age group.

Table 43: Overall experience of healthcare by age group.

Age	Experience	Respondents	Percentage
<18	N/A	2	25.0
	Very good	3	37.5
	Good	1	12.5
	Average	2	25.0
	Poor	0	0.0
	Very poor	0	0.0
18-24	N/A	1	14.29
	Very good	0	0.0

	Good	1	14.29
	Average	2	28.57
	Poor	2	28.57
	Very poor	1	14.29
	N/A	3	6.67
	Very good	7	15.56
25-34	Good	16	35.56
	Average	12	26.67
	Poor	3	6.67
	Very poor	4	8.89
	N/A	14	25.0
	Very good	4	7.14
35-44	Good	12	21.43
	Average	15	26.79
	Poor	5	8.93
	Very poor	6	10.71
	N/A	23	14.29
	Very good	19	11.8
45-54	Good	38	23.6
	Average	38	23.6
	Poor	20	12.42
	Very poor	23	14.29
	N/A	41	17.83
	Very good	40	17.39
55-64	Good	36	15.65
	Average	56	24.35
	Poor	26	11.3
	Very poor	31	13.48

65-69	N/A	25	24.51
	Very good	17	16.67
	Good	21	20.59
	Average	16	15.69
	Poor	13	12.75
	Very poor	10	9.8
70+	N/A	18	12.95
	Very good	32	23.02
	Good	30	21.58
	Average	22	15.83
	Poor	21	15.11
	Very poor	16	11.51

Overall experience of healthcare by gender.

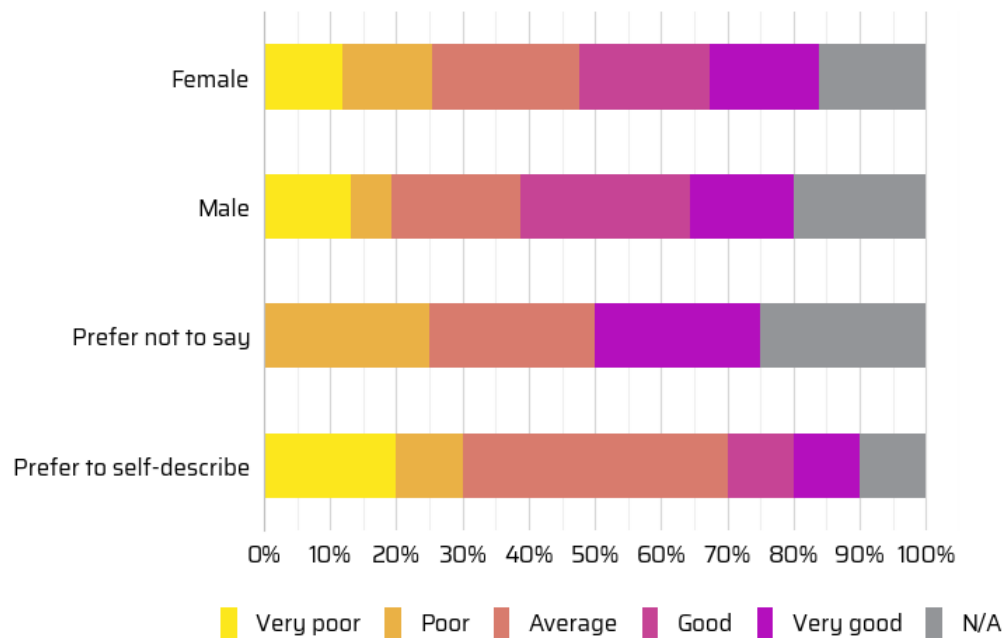


Figure 46: Overall experience of healthcare, broken down by gender.

Table 44: Overall experience of healthcare, broken down by gender.

Gender	Experience	Respondents	Percentage
Female	N/A	93	16.2
	Very good	95	16.55
	Good	113	19.69
	Average	127	22.13
	Poor	78	13.59
	Very poor	68	11.85
Male	N/A	32	20.0
	Very good	25	15.62
	Good	41	25.62
	Average	31	19.38
	Poor	10	6.25
	Very poor	21	13.12
Prefer not to say	N/A	1	25.0
	Very good	1	25.0
	Good	0	0.0
	Average	1	25.0
	Poor	1	25.0
	Very poor	0	0.0
Prefer to self-describe	N/A	1	10.0
	Very good	1	10.0
	Good	1	10.0
	Average	4	40.0
	Poor	1	10.0
	Very poor	2	20.0

Overall experience of healthcare by employment status.

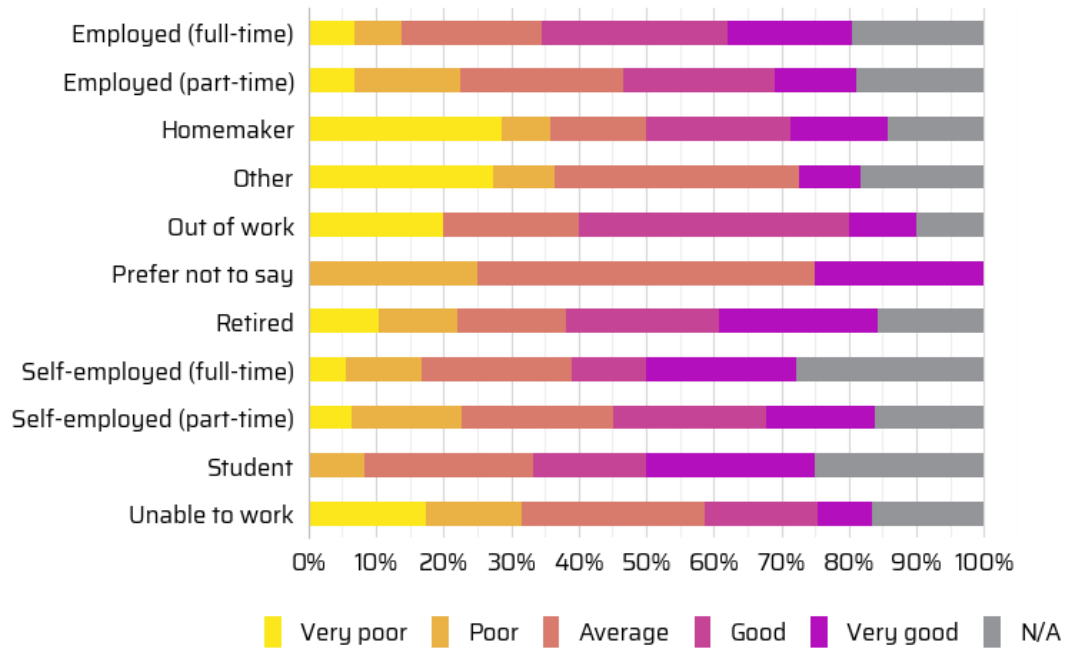


Figure 47: Overall experience of healthcare, broken down by employment status.

Table 45: Overall experience of healthcare, broken down by employment status.

Employment status	Experience	Respondents	Percentage
Employed (full-time)	N/A	17	19.54
	Very good	16	18.39
	Good	24	27.59
	Average	18	20.69
	Poor	6	6.9
	Very poor	6	6.9
Employed (part-time)	N/A	11	18.97
	Very good	7	12.07
	Good	13	22.41
	Average	14	24.14
	Poor	9	15.52
	Very poor	4	6.9

Homemaker	N/A	2	14.29
	Very good	2	14.29
	Good	3	21.43
	Average	2	14.29
	Poor	1	7.14
	Very poor	4	28.57
Other	N/A	2	18.18
	Very good	1	9.09
	Good	0	0.0
	Average	4	36.36
	Poor	1	9.09
	Very poor	3	27.27
Out of work	N/A	1	10.0
	Very good	1	10.0
	Good	4	40.0
	Average	2	20.0
	Poor	0	0.0
	Very poor	2	20.0
Prefer not to say	N/A	0	0.0
	Very good	1	25.0
	Good	0	0.0
	Average	2	50.0
	Poor	1	25.0
	Very poor	0	0.0
Retired	N/A	42	15.67
	Very good	63	23.51
	Good	61	22.76
	Average	43	16.04

	Poor	31	11.57
	Very poor	28	10.45
	N/A	5	27.78
	Very good	4	22.22
Self-employed (full-time)	Good	2	11.11
	Average	4	22.22
	Poor	2	11.11
	Very poor	1	5.56
	N/A	5	16.13
	Very good	5	16.13
Self-employed (part-time)	Good	7	22.58
	Average	7	22.58
	Poor	5	16.13
	Very poor	2	6.45
	N/A	3	25.0
	Very good	3	25.0
Student	Good	2	16.67
	Average	3	25.0
	Poor	1	8.33
	Very poor	0	0.0
	N/A	39	16.6
	Very good	19	8.09
Unable to work	Good	39	16.6
	Average	64	27.23
	Poor	33	14.04
	Very poor	41	17.45

Overall experience of healthcare by number of dependents.

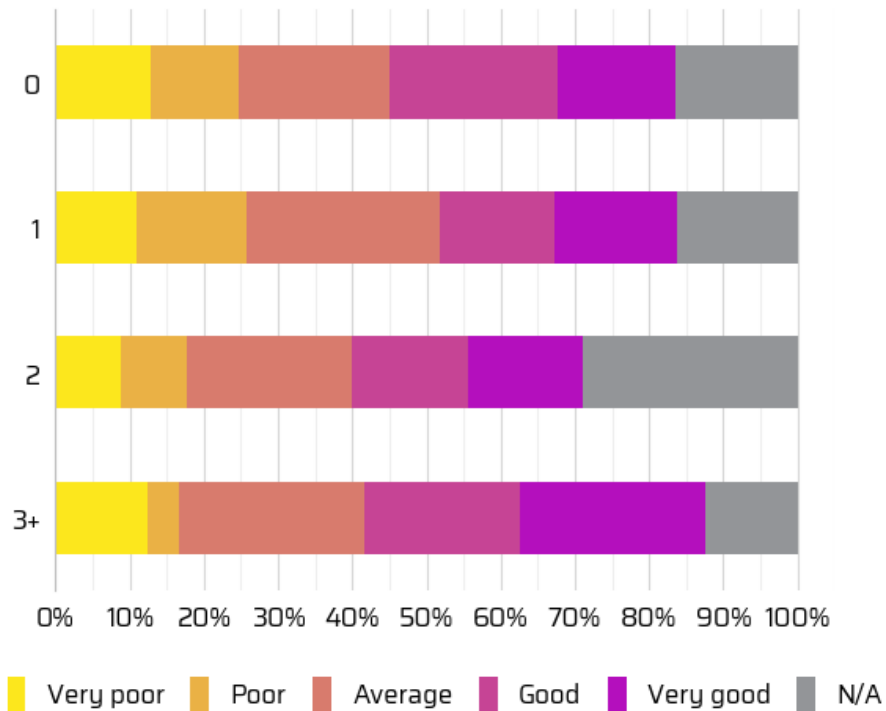


Figure 48: Overall experience of healthcare, broken down by number of dependents.

Table 46: Overall experience of healthcare, broken down by number of dependents.

Number of dependents	Experience	Respondents	Percentage
0	N/A	87	16.35
	Very good	85	15.98
	Good	120	22.56
	Average	109	20.49
	Poor	63	11.84
	Very poor	68	12.78
1	N/A	24	16.33
	Very good	24	16.33
	Good	23	15.65
	Average	38	25.85

2	Poor	22	14.97
	Very poor	16	10.88
	N/A	13	28.89
	Very good	7	15.56
	Good	7	15.56
	Average	10	22.22
	Poor	4	8.89
3+	Very poor	4	8.89
	N/A	3	12.5
	Very good	6	25.0
	Good	5	20.83
	Average	6	25.0
	Poor	1	4.17
	Very poor	3	12.5

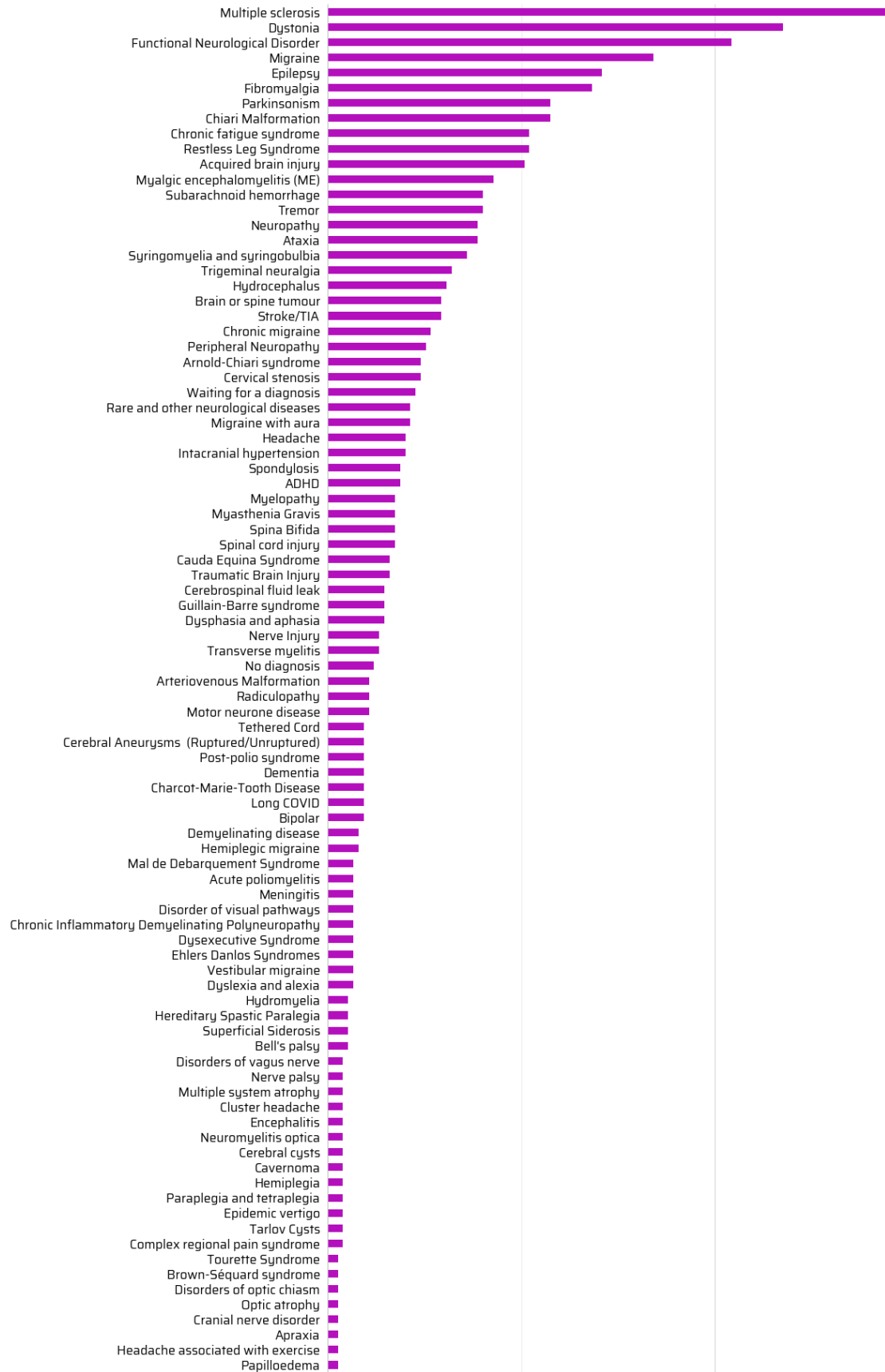
Demographics

Sample size.

Total number of respondents: 748

Neurological conditions.

NB: A single respondent may have multiple neurological conditions, therefore for this analysis the number of respondents per condition does not add up to the total number of respondents and the percentages do not add up to 100%. A total of 375 respondents, equating to 50.4% of the respondents that had answered this question, indicated that they have multiple (i.e., more than one) neurological conditions.



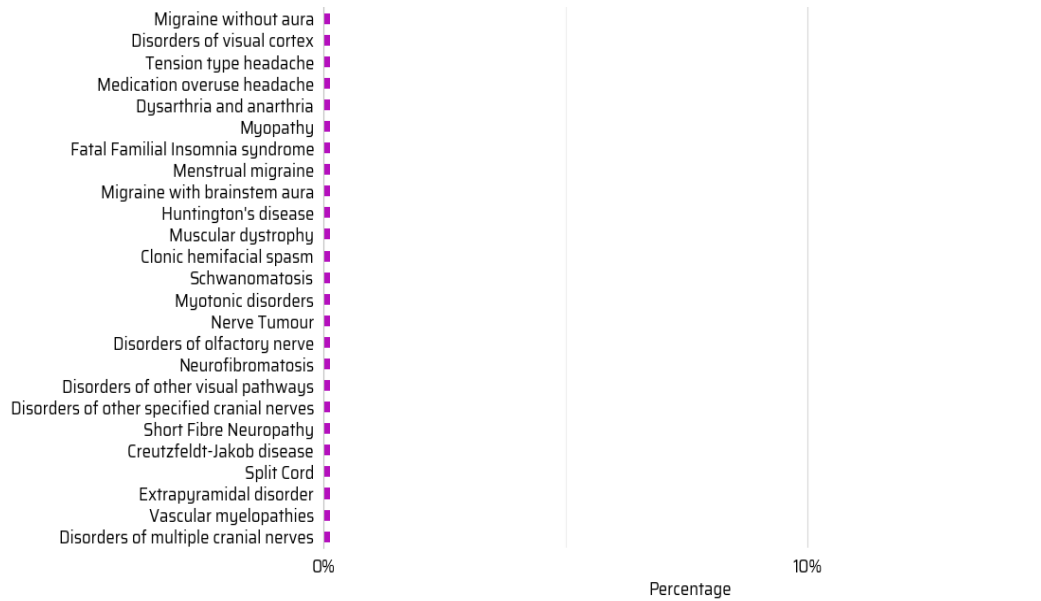


Figure 49: Neurological conditions respondents have been diagnosed with.

Table 47: Neurological conditions respondents have been diagnosed with.

Condition	Respondents	Percentage
Multiple sclerosis	108	14.44
Dystonia	88	11.76
Functional Neurological Disorder	78	10.43
Migraine	63	8.42
Epilepsy	53	7.09
Fibromyalgia	51	6.82
Parkinsonism	43	5.75
Chiari Malformation	43	5.75
Chronic fatigue syndrome	39	5.21
Restless Leg Syndrome	39	5.21
Acquired brain injury	38	5.08
Myalgic encephalomyelitis (ME)	32	4.28
Tremor	30	4.01
Subarachnoid hemorrhage	30	4.01
Neuropathy	29	3.88

Ataxia	29	3.88
Syringomyelia and syringobulbia	27	3.61
Trigeminal neuralgia	24	3.21
Hydrocephalus	23	3.07
Brain or spine tumour	22	2.94
Stroke/TIA	22	2.94
Chronic migraine	20	2.67
Peripheral Neuropathy	19	2.54
Arnold-Chiari syndrome	18	2.41
Cervical stenosis	18	2.41
Waiting for a diagnosis	17	2.27
Rare and other neurological diseases	16	2.14
Migraine with aura	16	2.14
Headache	15	2.01
Intracranial hypertension	15	2.01
Spondylosis	14	1.87
ADHD	14	1.87
Myelopathy	13	1.74
Myasthenia Gravis	13	1.74
Spina Bifida	13	1.74
Spinal cord injury	13	1.74
Cauda Equina Syndrome	12	1.6
Traumatic Brain Injury	12	1.6
Guillain-Barre syndrome	11	1.47
Dysphasia and aphasia	11	1.47
Cerebrospinal fluid leak	11	1.47
Transverse myelitis	10	1.34

Nerve Injury	10	1.34
No diagnosis	9	1.2
Arteriovenous Malformation	8	1.07
Radiculopathy	8	1.07
Motor neurone disease	8	1.07
Tethered Cord	7	0.94
Cerebral Aneurysms (Ruptured/Unruptured)	7	0.94
Post-polio syndrome	7	0.94
Dementia	7	0.94
Charcot-Marie-Tooth Disease	7	0.94
Long COVID	7	0.94
Bipolar	7	0.94
Demyelinating disease	6	0.8
Hemiplegic migraine	6	0.8
Mal de Debarquement Syndrome	5	0.67
Acute poliomyelitis	5	0.67
Meningitis	5	0.67
Disorder of visual pathways	5	0.67
Chronic Inflammatory Demyelinating Polyneuropathy	5	0.67
Dysexecutive Syndrome	5	0.67
Ehlers Danlos Syndromes	5	0.67
Vestibular migraine	5	0.67
Dyslexia and alexia	5	0.67
Hereditary Spastic Paralegia	4	0.53
Hydromyelia	4	0.53
Superficial Siderosis	4	0.53

Bell's palsy	4	0.53
Complex regional pain syndrome	3	0.4
Tarlov Cysts	3	0.4
Cavernoma	3	0.4
Epidemic vertigo	3	0.4
Paraplegia and tetraplegia	3	0.4
Hemiplegia	3	0.4
Neuromyelitis optica	3	0.4
Cerebral cysts	3	0.4
Disorders of vagus nerve	3	0.4
Nerve palsy	3	0.4
Multiple system atrophy	3	0.4
Cluster headache	3	0.4
Encephalitis	3	0.4
Papilloedema	2	0.27
Headache associated with exercise	2	0.27
Apraxia	2	0.27
Cranial nerve disorder	2	0.27
Optic atrophy	2	0.27
Disorders of optic chiasm	2	0.27
Brown-Séquard syndrome	2	0.27
Tourette Syndrome	2	0.27
Vascular myelopathies	1	0.13
Extrapyramidal disorder	1	0.13
Split Cord	1	0.13
Creutzfeldt-Jakob disease	1	0.13
Short Fibre Neuropathy	1	0.13

Disorders of other specified cranial nerves	1	0.13
Disorders of other visual pathways	1	0.13
Neurofibromatosis	1	0.13
Disorders of olfactory nerve	1	0.13
Nerve Tumour	1	0.13
Myotonic disorders	1	0.13
Migraine without aura	1	0.13
Clonic hemifacial spasm	1	0.13
Muscular dystrophy	1	0.13
Huntington's disease	1	0.13
Migraine with brainstem aura	1	0.13
Menstrual migraine	1	0.13
Fatal Familial Insomnia syndrome	1	0.13
Myopathy	1	0.13
Dysarthria and anarthria	1	0.13
Medication overuse headache	1	0.13
Tension type headache	1	0.13
Disorders of visual cortex	1	0.13
Schwanomatosis	1	0.13
Disorders of multiple cranial nerves	1	0.13

Multiple neurological conditions.

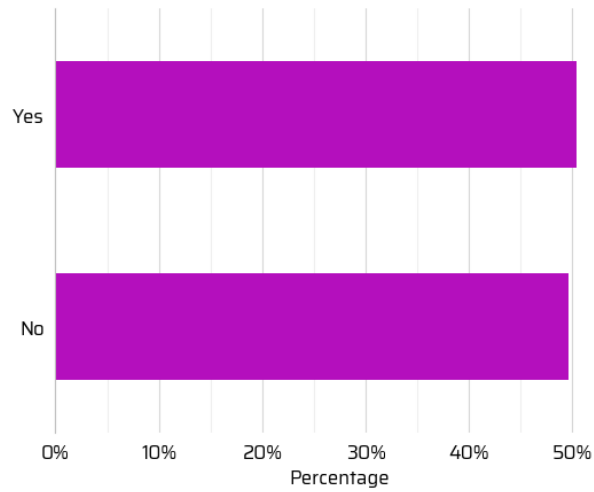


Figure 50: Whether respondents were diagnosed with multiple neurological conditions.

Table 48: Whether respondents were diagnosed with multiple neurological conditions.

Multiple neurological conditions	Respondents	Percentage
Yes	375	50.4
No	369	49.6

Number of non-neurological co-occurring conditions.

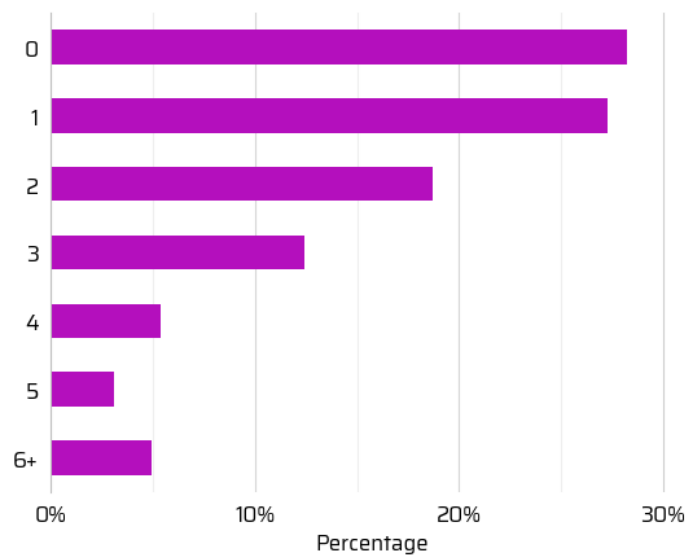


Figure 51: Number of non-neurological conditions that respondents were diagnosed with that co-occur with their neurological condition(s).

Table 49: Number of non-neurological conditions that respondents were diagnosed with that co-occur with their neurological condition(s).

Number of conditions	Respondents	Percentage
0	211	28.21
1	204	27.27
2	140	18.72
3	93	12.43
4	40	5.35
5	23	3.07
6+	37	4.95

Recency of diagnosis.

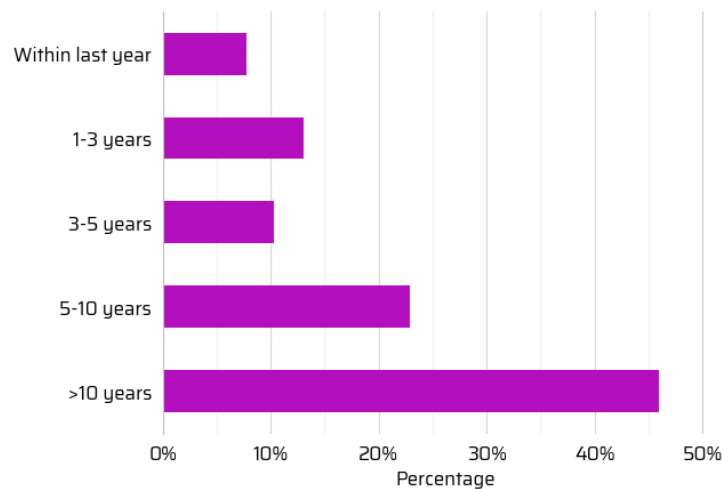


Figure 52: Recency of the respondents' first diagnosis with a neurological condition diagnosis.

Table 50: Recency of the respondents' first diagnosis with a neurological condition diagnosis.

Recency	Respondents	Percentage
Within last year	58	7.75
1-3 years	98	13.1
3-5 years	77	10.29
5-10 years	171	22.86
>10 years	344	45.99

Location of the respondents.



Figure 53: Location of the respondents.

Table 51: Location of the respondents.

Regions	Respondents	Percentage
Midlands	131	17.01
South East	126	16.36
East of England	96	12.47
North East and Yorkshire	94	12.21
South West	80	10.39
London	67	8.7
Scotland	65	8.44
North West	53	6.88
Wales	42	5.45
Northern Ireland	11	1.43
Isle of Man	3	0.39
Channel Islands	2	0.26

NB: The regions in England are further divided into "NHS England Regions". We asked respondents for the first part of their postcodes. 22 of the respondents have postcodes that span across two different regions on the map. e.g. some postcodes span across both London and South East, or both Wales and Midlands, etc. Therefore, we do not have the information about which of the two regions these respondents are actually in. For Figure 5 and Table 5, if a postcode spans across two areas, we add 1 to each of these areas. Some respondents did not provide their postcodes or offered invalid postcodes, and therefore were not included in this analysis.

Age.

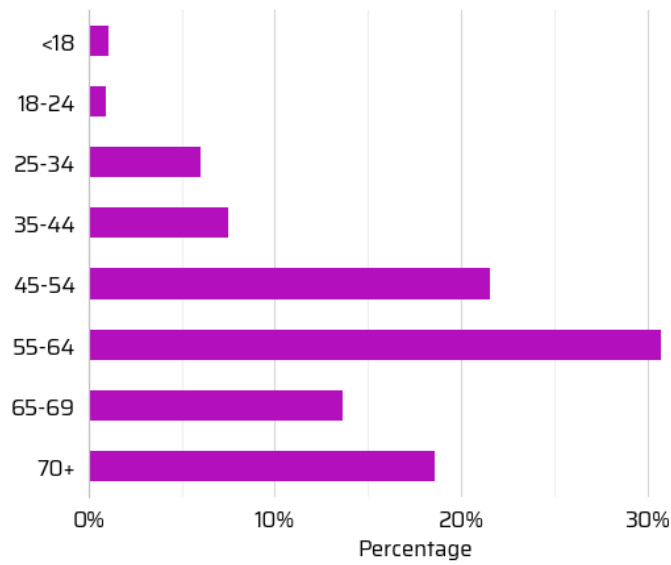


Figure 54: Age of respondents.

Table 52: Age of respondents.

Age	Respondents	Percentage
<18	8	1.07
18-24	7	0.94
25-34	45	6.02
35-44	56	7.49
45-54	161	21.52
55-64	230	30.75
65-69	102	13.64
70+	139	18.58

Ethnic group.

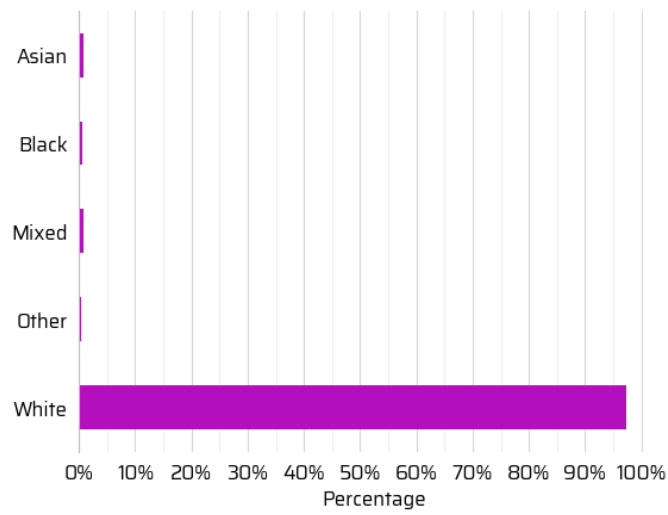


Figure 55: Ethnic group of respondents.

Table 53: Ethnic group of respondents.

Ethnic group	Respondents	Percentage
Asian	6	0.8
Black	5	0.67
Mixed	6	0.8
Other	3	0.4
White	728	97.33

Gender.

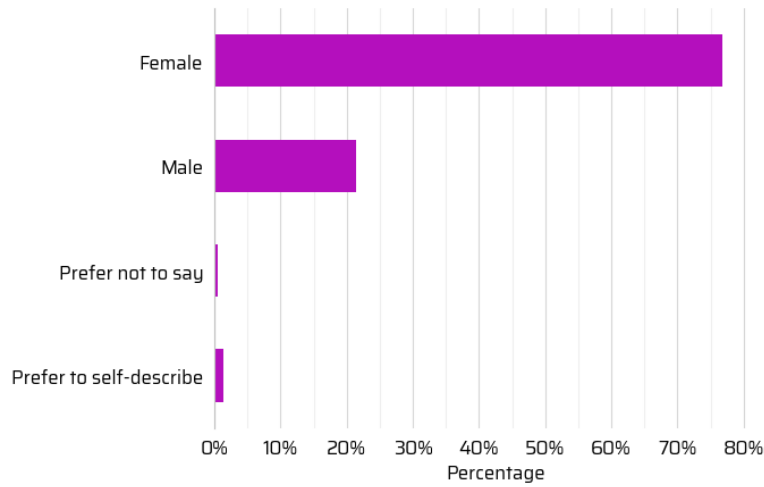


Figure 56: Gender of respondents.

Table 54: Gender of respondents.

Gender	Respondents	Percentage
Female	574	76.74
Male	160	21.39
Prefer not to say	4	0.53
Prefer to self-describe	10	1.34

Sexual orientation.

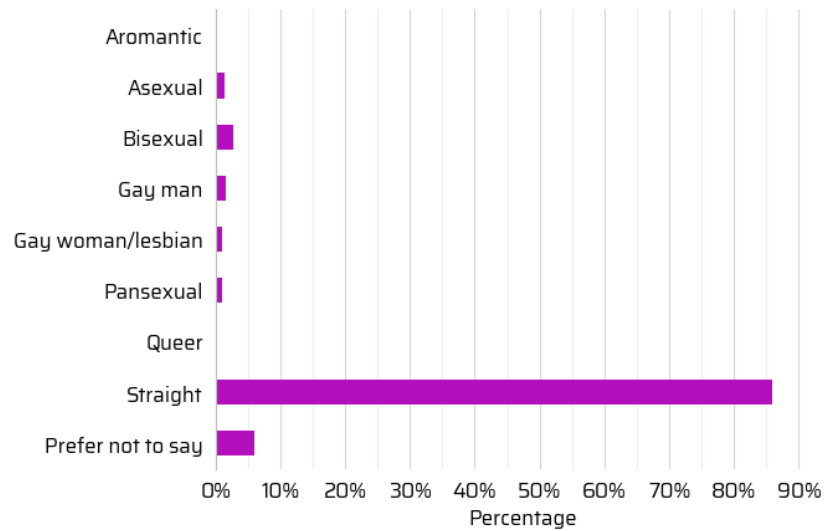


Figure 57: Sexual orientation of respondents.

Table 55: Sexual orientation of respondents.

Sexual orientation	Respondents	Percentage
Aromantic	2	0.27
Asexual	10	1.35
Bisexual	20	2.7
Gay man	12	1.62
Gay woman/lesbian	7	0.94
Pansexual	8	1.08
Queer	1	0.13
Straight	636	85.83
Prefer not to say	45	6.07

Employment status.

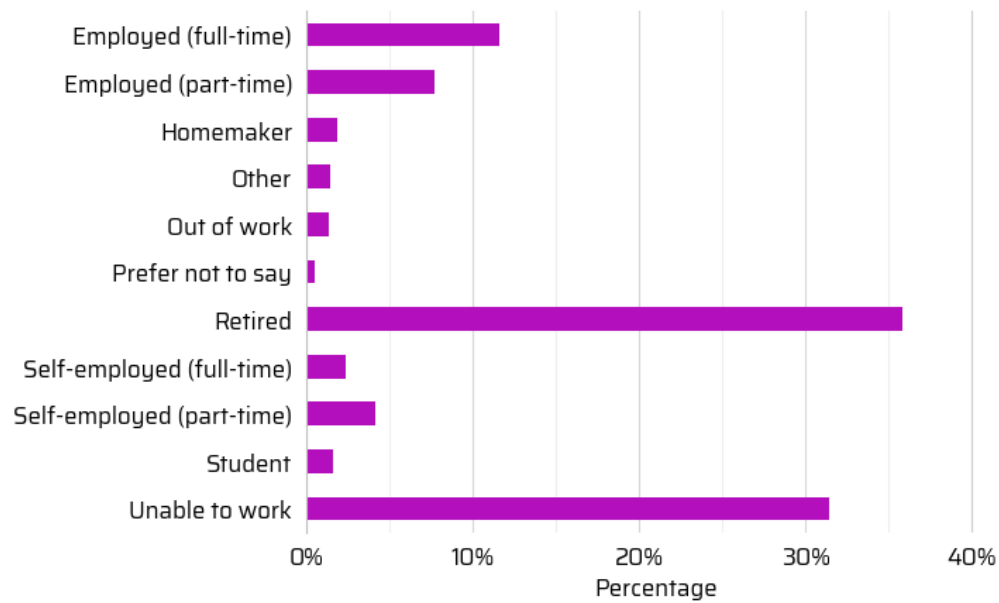


Figure 58: Location of the respondents.

Table 56: Location of the respondents.

Employment status	Respondents	Percentage
Employed (full-time)	87	11.63
Employed (part-time)	58	7.75
Homemaker	14	1.87
Other	11	1.47
Out of work	10	1.34
Prefer not to say	4	0.53
Retired	268	35.83
Self-employed (full-time)	18	2.41
Self-employed (part-time)	31	4.14
Student	12	1.6
Unable to work	235	31.42

Number of dependents.

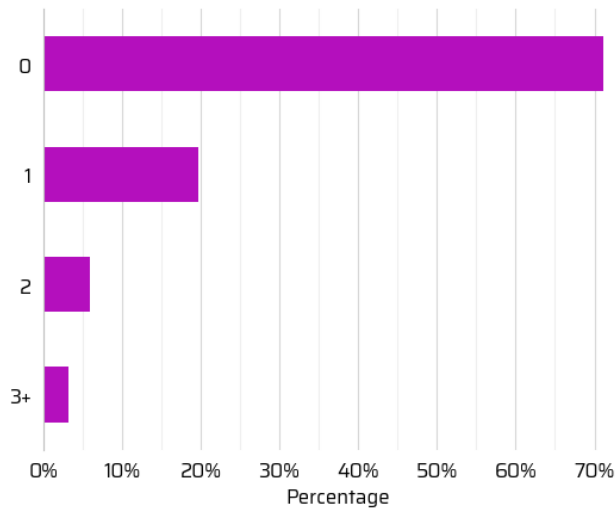


Figure 59: Number of dependents of respondents.

Table 57: Number of dependents of respondents.

Number of dependents	Respondents	Percentage
0	532	71.12
1	147	19.65
2	45	6.02
3+	24	3.21

Receiving care or support.

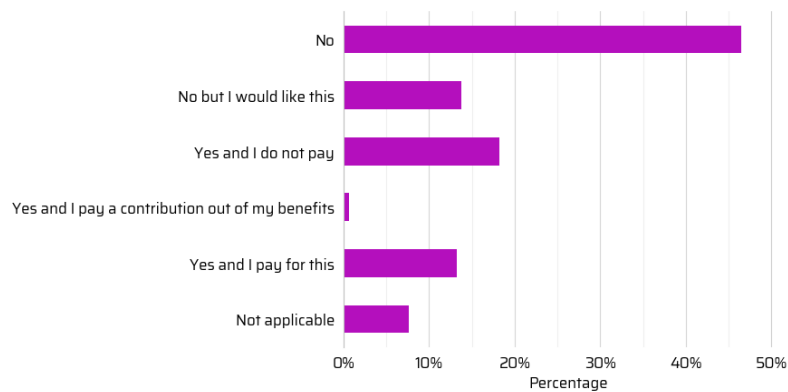


Figure 60: Whether respondents are receiving care or support.

Table 58: Whether respondents are receiving care or support.

Receive care/support	Respondents	Percentage
No	348	46.52
No but I would like this	103	13.77
Yes and I do not pay	136	18.18
Yes and I pay a contribution out of my benefits	5	0.67
Yes and I pay for this	99	13.24
Not applicable	57	7.62

Appendix A - Survey Questions

Question	Response options		
Are you filling in this questionnaire for yourself?	Yes	No	

About your condition(s)				
Which year were you diagnosed with your primary neurological condition?	Free text			
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			
	None	1	2	3

Do you live with conditions other than your neurological condition(s)? If so, how many:	4	5	6+
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Shared issues and symptoms

There are over 600 different neurological conditions/symptoms. Many issues are specific to a particular condition, such differences are of course important to identify to inform positive change. There are, however, numerous issues that are shared by many with neurological conditions, as well as some neurological conditions that are symptoms of another.

Identifying the shared daily realities of the 1 in 6 people with a neurological condition in UK will be hugely powerful for informing positive change.

<p>Please indicate which of the following symptoms and issues you have experienced? Please tick all that apply.</p>	Problems with eyesight or spatial problems
	Memory problems
	Personality change
	Problems concentrating and attention
	Problems with thinking, learning and planning
	Communication and language problems
	Difficulties regulating emotions
	Relationship problems
	Problems with impulse control and behaviour
	Pain
	Tremors
	Muscle spasms, stiffness and weakness

	Anxiety
	Depression
	Problems with hearing
	Fatigue
	Numbness and/or tingling
	Bladder and bowel issues
	Paralysis
	None of the above

How far do you travel for appointments?

The daily realities that you share with us are being presented to the NHS, national and local government, and all forms of service providers to inform positive change. As part of wider NHS reforms there are currently active discussions around how far people must travel to get to their specialist appointments.

On average, how long does it take you to travel to health or care appointments for your neurological condition(s)?	0-15 minutes	15-30 minutes
	30 - 60 minutes	1-2 hrs
	More than 2 hours	
Overall, how difficult do you find it to travel to the majority of your appointments for your neurological condition(s)?	Very difficult	Difficult
	Not very difficult	Not at all difficult
Please tell us more about why you find it difficult (or not) to travel to the majority of your appointments for your neurological condition(s).	Free text	

About your recent experiences of treatment and support

We would like to find out about your recent experience of care and support services. We ask these questions in every survey to help us monitor changes over time.				
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		
Last time you wanted to see or speak to a specialist about your neurological condition, what did you want to do?	See a specialist at the clinic			
	Speak to a specialist on the phone			
	Have someone visit me at my home			
	I didn't mind / wasn't sure what I wanted			
Were you able to speak to or see a specialist?	Yes		No	
How convenient was the appointment you were able to get?	Very convenient			
	Fairly convenient			
	Not very convenient			
	Not at all convenient			
If you were not able to get an appointment or the appointment you were offered wasn't convenient, why was that?	There weren't any appointments for the day I wanted			
	There weren't any appointments for the time I wanted			
	I could not see my preferred specialist			
	I could not book ahead			
	Another reason			
Please tell us the reason why you could not get an appointment or were not offered a convenient one.	Free text			
What did you do on that occasion?	Went to the appointment I was offered			
	Got an appointment for a different day			
	Had a consultation over the phone			
	Went to A&E / a walk-in centre			

	Saw a pharmacist			
	Decided to contact my specialist another time			
	Didn't see or speak to anyone			
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 Allied Health Professional (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 Allied Health Professional (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 Allied Health Professional (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 Allied Health Professional (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 Allied Health Professional (AHP)
How was your fifth medical appointment delivered?	Other
	Phone
	Videoconference
	Via text/WhatsApp
	Face to face
How helpful was your fifth medical appointment?	Other
	It was helpful
	It was not helpful
Who was your sixth medical appointment with?	Don't Know
	Neurologist
	Specialist Nurse
	Physiotherapist
	Speech and Language Therapist

	Occupational Therapist
	Psychologist/ Psychiatrist
	GP
	Social Services
	Neurosurgery
	Other Allied Health Professional (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 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
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
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 Conditions

Abdominal migraine	Acquired brain injury	Acute poliomyelitis
ADHD	Agnosia	Amoebic brain abscess
Apraxia	Arnold-Chiari syndrome	Arteriovenous Malformation
Ataxia	Bell's palsy	Bipolar
Brain or spine tumour	Brown-Séquard syndrome	Cauda Equina Syndrome
Cavernoma	Central Pontine Myelinolysis	Cerebral Aneurysms (Ruptured/Unruptured)
Cerebral cysts	Cerebrospinal fluid leak	Cervical stenosis
Chagas' disease	Charcot-Marie-Tooth Disease	Chiari Malformation
Chronic fatigue syndrome	Chronic Inflammatory Demyelinating Polyneuropathy	Chronic migraine
Clonic hemifacial spasm	Cluster headache	Complex regional pain syndrome
Cranial nerve disorder	Creutzfeldt-Jakob disease	Cyclical vomiting syndrome
Cysticercosis of central nervous system	Dementia	Demyelinating disease
Disorder of visual pathways	Disorders of hypoglossal nerve	Disorders of multiple cranial nerves
Disorders of olfactory nerve	Disorders of optic chiasm	Disorders of other specified cranial nerves
Disorders of other visual pathways	Disorders of vagus nerve	Disorders of visual cortex
Down's Syndrome	Dysarthria and anarthria	Dysexecutive Syndrome
Dyslexia and alexia	Dysphasia and aphasia	Dystonia
Eaton-Lambert syndrome	Ehlers Danlos Syndromes	Encephalitis
Epidemic vertigo	Epilepsy	Extradural and subdural abscess

Extrapyramidal disorder	Facial myokymia	Faetal Alcohol Spectrum Disorders (FASD)
Fatal Familial Insomnia syndrome	Fibromyalgia	Functional Neurological Disorder
Geniculate ganglionitis	Guillain-Barre syndrome	Headache
Headache associated with exercise	Hemicrania continua	Hemicranial Corrina
Hemiplegia	Hemiplegic migraine	Hereditary Spastic Paralegia
High altitude headache	Huntington's disease	Hydrocephalus
Hydromyelia	Hypnic headache	Intacranial hypertension
Intracranial abscess and granuloma	Intracranial and intraspinal abscess and granuloma in diseases classified elsewhere	Intracranial and intraspinal phlebitis and thrombophlebitis
Kennedy's disease	Leukoencephalitis	Long COVID
Mal de Debarquement Syndrome	Malaria	Medication overuse headache
Melkersson's syndrome	Meningeal tuberculoma	Meningitis
Menstrual migraine	Migraine	Migraine with aura
Migraine with brainstem aura	Migraine without aura	Motor neurone disease
Multiple sclerosis	Multiple system atrophy	Muscular dystrophy
Myalgic encephalomyelitis (ME)	Myasthenia Gravis	Mycoses
Myelopathy	Myopathy	Myositis
Myotonic disorders	Narcolepsy and cataplexy	Nerve Injury
Nerve palsy	Nerve Tumour	Neurofibromatosis
Neuromyelitis optica	Neuropathy	Neurosarcoidosis
No diagnosis	Optic atrophy	Papilloedema

Paraplegia and tetraplegia	Parkinsonism	Peripheral Neuropathy
Post-polio syndrome	Postzoster neuralgia	Progressive multifocal leukoencephalopathy
Rabies	Radiculopathy	Rare and other neurological diseases
Refsum's Disease	Restless Leg Syndrome	Schwanomatosis
Short Fibre Neuropathy	Spina Bifida	Spinal cord injury
Spinal muscular atrophy	Split Cord	Spondylosis
Sporadic Fatal Insomnia	Stroke/TIA	Subacute sclerosing panencephalitis
Subarachnoid hemorrhage	Superficial Siderosis	Syringomyelia and syringobulbia
Tarlov Cysts	Tension type headache	Tethered Cord
Tourette Syndrome	Toxic encephalopathy	Toxoplasma meningoencephalitis
Transverse myelitis	Traumatic Brain Injury	Tremor
Trigeminal neuralgia	Tuberculous meningitis	Vascular myelopathies
Vestibular migraine	Waiting for a diagnosis	