NeuroLifeNow
It's time to make your story heard

September – October 2023 Full Insights Report

The impact neurological conditions have on lives, in addition to NHS strikes and the winter months.

Brain & Spine Foundation
THE NEUROLOGICAL ALLIANCE
COMMUNITY FUND

The Brain & Spine Foundation registered charity no. 1098528

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 captures 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

People affected by neurological conditions always tell us they are under considerable pressure over the winter period, as the ability to access health and care services often becomes even more difficult, fluctuating temperatures have a direct impact on symptoms, and mental health can, and often does, worsen.

Concerns going into winter.

In September and October, hundreds of you told us just how worried they were going into winter 2023. The impacts on mental health and finances particularly stark.

“I’m dreading the whole energy bills game again. As someone on legacy benefits, I don’t qualify for all the uplifts/cost of living handouts - this is discrimination on a wide scale…. I live alone, I don’t have a partner or family to bear the cost burden of rent, bills etc. Single disabled folk - where’s the help for us if we don’t tick the right boxes?”

“Dark, depressive thoughts.”

“Being isolated at home as the cold makes my symptoms worse.”

The impact of the NHS strikes

For many, strike action in the NHS only added to the pressures of winter. Whilst many of you spoke of your support for those striking – the importance of appropriate support and reimbursement for NHS workers is seen as critical to good care – you also spoke of waits for support being extended, sometimes as a direct impact of the strikes.

“My botox injections will be over 6 weeks late, I am already in pain and tremors getting very hard to cope with.”

“Appointments cancelled and new ones made. Added negatively to my symptoms added to their intensity, duration and increased my stress levels hugely.”

“I stand with the people who strike. Their work has not been acknowledged for a long time. In this case, I would be happy to wait longer to get the care I need.”

Together with NHS Healthwatch England, Age UK, NHS Confederation, National Voices and the Patients Association, we call on both Government and the British Medical Association (BMA) to get back to the negotiating table, believing that further strikes would be a major blow for the service already grappling with record waiting lists, winter pressures and the financial fall out of previous industrial action.

Living with neurological conditions

Finally, and most importantly, you were clear in your exasperation and your pain of the daily realities of living with a neurological condition – the realities of daily unpredictable changes to how you think, feel and move, as well as how your condition takes its toll not only on you but also those closest to you.

“I have changed completely, friends have gone, I look ok but inside I am scared all the time.”

“I can no longer enjoy the things I used to do, like walking, hiking, rambling, keep fit.”

“It is stopping me from living my life.”

“Friends & family not interested in my lived experience. It’s very lonely.”

We are here for you. And we are determined for you, the neurological community, to have access to the right support, and the policy and political investment that is so long overdue.

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 our specialist nurse run helpline on **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)

Contents

Key Findings

685 people with neurological conditions across the UK responded. **164 conditions were represented**. Multiple sclerosis (MS), Dystonia and Functional Neurological Disorder (FND) were the most common conditions represented.

Over 96.79% of respondents identified as White British. Neurological conditions affect everyone, regardless of age, gender, sex, race or ethnicity. **Addressing the lack of ethnic and racial diversity of respondents is a key priority of the NeuroLifeNow programme.**

28% of respondents said they had been impacted by strikes this year. 36% of people with multiple conditions said this compared to 20% of respondents with one neurological condition.

69% of people said their neurological condition impacted their life to a great or large extent. This increases to 77% for people living with multiple neurological conditions.

Nearly half (48%) of people said they felt anxious. A quarter (25%) said they felt hopeless. **57% of people said their mental health needs were only being met** to a small extent or not at all.

Half (50%) of people said they had a good or very good overall experience of healthcare in the past eight weeks. 7% had had 6 or more medical appointments.

77% of people found their appointments useful.

Three quarters (75%) were held face to face, 22% were held on the telephone. Most appointments reported to us were with a GP.

10% of people with multiple neurological conditions had visited A&E in the past eight weeks, compared to 5% of people with one neurological condition.

****Trigger warnings****
Please note this report contains material of a highly sensitive nature including references to suicide and death that may be triggering for some individuals.

The impact of the NHS strikes

Have the NHS strikes had an impact on healthcare and support?

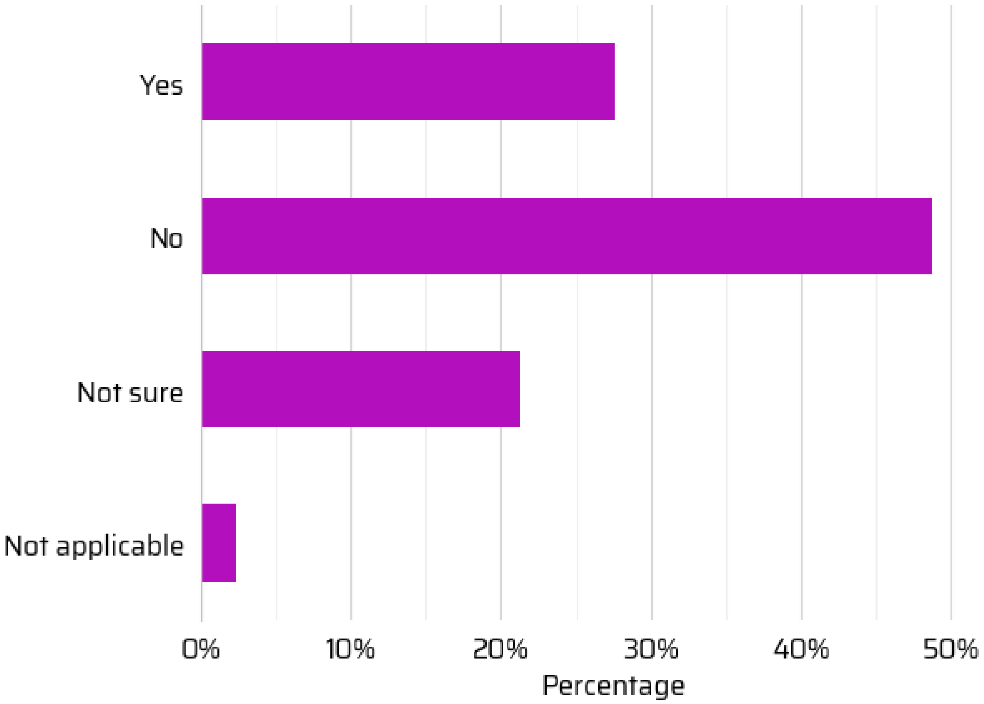


Figure 1: Have the NHS strikes had an impact on healthcare and support?

Table 1: Have the NHS strikes had an impact on healthcare and support?

Response	Respondents	Percentage
Yes	189	27.59
No	334	48.76
Not sure	146	21.31
Not applicable	16	2.34

How have the NHS strikes had an impact on your healthcare and support?

Word cloud

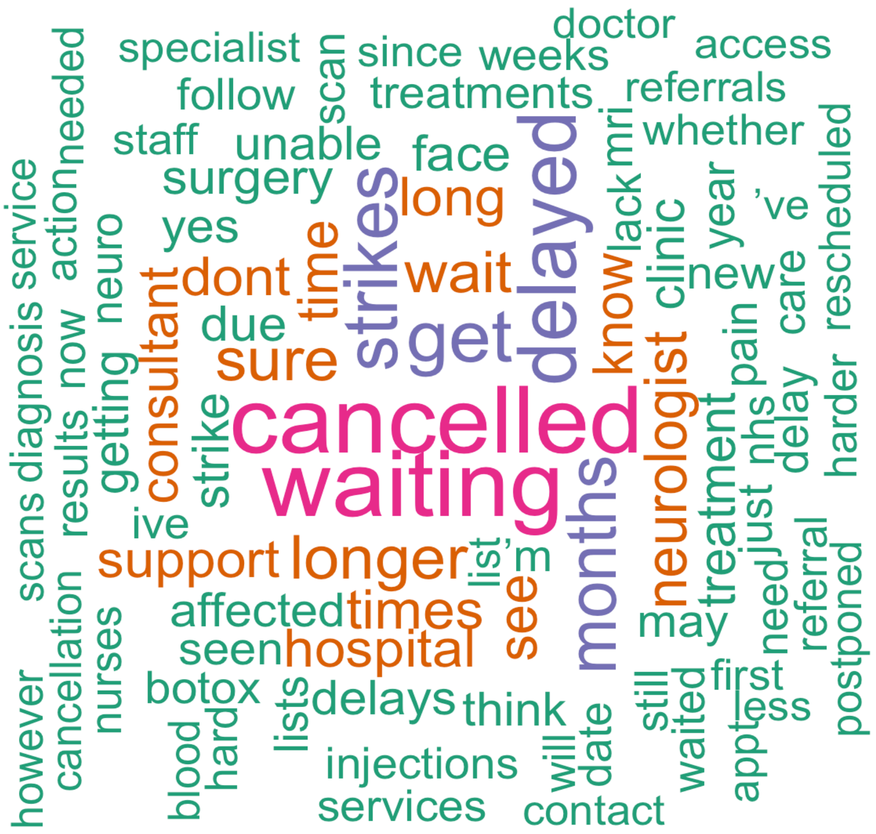


Figure 2: Word cloud showing key words used by respondents related to impacts of neurological conditions on employment.

Thematic analysis

Thematic analysis was conducted for responses to the question. The following themes emerged:

Theme 1: Delays and cancellations for appointments.

- Long waiting list for appointments to get diagnosis and treatment.
- Delay in getting tested or getting test results.
- Delay in getting diagnosis.
- Delay in getting treatment or surgery.

- Delay in annual review and less frequent consultation
- Appointments cancelled/rescheduled.

Theme 2: Longer waiting time at health facilities.

Theme 3: Problems getting to the hospital.

- Hospital transport cancelled.
- Long waiting time for ambulance.

Theme 4: Not getting enough support.

- Cannot reach hospital/services.
- No access to support at all.
- Delay in getting referrals.
- No follow-up
- No face-to-face appointment.
- Unable to see GP.
- Lack of physiotherapy or osteopathy.
- Went to private.

Theme 5: Confusion.

Theme 6: Mental health affected.

Theme 7: Supportive of the strike.

Theme 8: No impact or not sure.

Theme 1: Delays and cancellations for appointments.

The first theme that emerged was delays and cancellations for appointments. Respondents reported that they had faced delays and cancellations for their appointments, which impacted their access to healthcare.

Long waiting list for appointments to get diagnosis and treatment.

> "Waiting too long for urgent appointment, months not weeks."

> "Have to wait longer for appointments."

Delay in getting tested or getting test results.

> "As I am reliant on a manual wheelchair for mobility and my own independence the scan to confirm if I have a right rotor cuff tear has yet to be

confirmed. I have now been waiting 5 months and despite carrying out exercises given by GP to alleviate pain and aid shoulder repair pain has increased."

"Delayed scans and finding the autoimmune causing my primary biliary cirrhosis. 2+years waiting for neurosurgeon team input for increased nerve entrapment/degenerating cervical myelopathy."

Delay in getting diagnosis.

"Getting a further diagnosis on a hip replacement."

Delay in getting treatment or surgery.

"My operation to correct a left Ulnar nerve entrapment was cancelled. Now scheduled for 27 November, first diagnosed 28 June. Will be 25 weeks from diagnosis and 18 months from when I first reported symptoms."

"I have been waiting for a year for a knee replacement and because I am now lopsided due to the angle of my right leg from the knee down my scoliosis has become more painful. I am on a list for surgery but looks as if I will have to wait until after Christmas."

"My botox injections will be over 6 weeks late,i am already in pain and tremors getting very hard to cope with."

"I have Botox injections every 3 months. This time it's 4 months."

Delay in annual review and less frequent consultation.

"My annual consultant review is now 14 months since the last one."

"My yearly check up with my neurologist is later than usual."

"I only get my consultations every 4 months instead of 3. This includes my botulinum injections."

"My consultant neurologist has been covering the strikes, and as such has had less time for his CSF Leak clinic patients (Spontaneous Intracranial Hypotension you don't have listed)."

Appointments cancelled or rescheduled.

“I had my appointments cancelled 5 times, sometimes a couple of times a day.”

“I have had 3 hospital appointments cancelled. One appointment has been cancelled twice.”

“I’ve waited 8 months for a face to face appointment with gall bladder surgeon. It was cancelled in August and I can’t get a new date.”

“Botox OPD appointment cancellation. I need this to manage spasms & spasticity.”

“I have had appointments delayed or cancelled because of strikes.”

Theme 2: Longer waiting time at health facilities.

The strikes have also resulted in longer waiting time when the respondents went to health facilities, such as hospitals, clinics and A&Es.

“Clinic wait time, >1hr due time.”

” I have also had admissions which shouldn’t have been very long last days-weeks because there aren’t enough doctors for rounds.”

“I ended up in A&E on the weekend of a Junior Doctors strike - I waited for 8 hours even after being brought in by ambulance, the doctor I saw was really dismissive and reminded me of all the gaslighting specialists I dealt with before I was diagnosed with my rare neuro disease.”

Theme 3: Problems getting to the hospital.

Due to the strikes, respondents also had problems getting to the hospitals, or had to take into account the possibilities of cancellations of their transport due to the strikes.

Hospital transport cancelled.

“Hospital transport to specialist clinics a long distance away was cancelled, leading to appointment cancellations.”

“Going to London University college hospital for an appointment, however I checked beforehand and check the train and had a open return just in case.”

Long waiting time for ambulance.

“Had to wait 11 hours for an ambulance after suffering a stroke.”

Theme 4: Not getting enough support.

Another theme that emerged suggested that the respondents have not received enough support for their conditions due to the strikes. As a result, some of the respondents have opted for private healthcare.

Cannot reach hospital or health services.

“Unable to speak with professionals at times of strikes.”

“Patients cannot directly contact the consultants they need to speak to.”

“Neuro impossible to contact.”

No access to support at all

“I have no access to support help or any health care.”

“I [do] not have any access to adult social service and occupation therapist.”

“Not being heard or listened to.”

“Unable to get an appointment.”

Delay in getting referrals.

“Yes, they’ve delayed…..referrals to social Work department for care / support needed.”

No follow-up.

"I have seen epilepsy nurses on the dates identified, but have had no response about my tremor."

"Referred to neurologist 6 months ago but heard nothing."

"Did not get my follow up call from consultant on two occasions."

No face-to-face appointment.

"Phone consultations have been offered but it isn't the same as face to face."

"GP doing nearly all telephone appointments instead of face to face."

"phone call appt instead of face to face."

Unable to see GP

"G.P. appointments are still non-existent."

"Difficulty getting treatment from GP."

"hard to get appointments with gp."

Lack of physiotherapy or osteopathy.

"I have not had an appointment to see the osteopathic specialist re my back since February and I was supposed to have one six months after the February appointment."

"Lack of physios."

"Waiting for physio for hand therapy."

Went to private.

"Very extended wait for an appointment, necessitating me to make a private appointment."

"Waiting times so went paid for multiple private appts for multiple conditions (migraine & menopause)."

Theme 5: Confusion.

The strikes have also resulted in confusion regarding respondents' appointments and conditions.

> "The NHS is slow and making errors, it's took them a year to realise they haven't checked something - more waiting and pain for me. They have sent documents to a 3rd party and also forgot to refer me in the first instance in 2020"

> "Turned up for an appointment for laser eye treatment on a day that I'd checked the clinic was working to be told I wasn't on the list (in spite of having the letter with me.)"

> "It may be the reason why all my appointments seem to be in limbo with nobody really knowing what is going on. Delayed urgent treatments?"

> "Complex as neurology services lack already-no named GP - fearful as another data error-communication breakdown with an apology letter."

Theme 6: Mental health affected.

Some respondents also reported how the strikes affected their mental health.

> "…anxiety about being able to get further treatment."

> "Appointments cancelled and new ones made. Added negatively to my symptoms added to their intensity, duration and increased my stress levels hugely."

> "Strikes make me feel like I don't matter and I am worthless."

Theme 7: Supportive of the strike

Although the strikes may have affected the respondents' healthcare and support, they received, some showed their support for the strikes.

"I stand with the people who strike. Their work has not been acknowledged for a long time. In this case, I would be happy to wait longer to get the care I need."

"It was harder to get to speak to nurses and doctors however I fully support the strikes and as someone who is unwell I have seen the pressure facing the NHS first hand and we as patients suffer because of the lack of funding and resources available to the NHS."

Theme 8: No impact or not sure

Some respondents reported that the strikes had no impact on their health care and support. Others admitted that they were not sure if the pre-existing difficulties they faced were due to the strikes.

"I don't think I've been directly impacted as such, I've not had any appointments cancelled and not needed any medical help on those days so can't say that I have been unable to access support."

"Waiting times are delayed anyway so am unsure if strikes are impacting"

"Not sure whether the waiting lists I am on would be shorter if there had been no strikes."

"My appointment has been cancelled though this may not be directly linked to the strikes and more linked to the general underfunding of the NHS as a whole, as almost every appointment has been cancelled and rescheduled since 2019."

Concerns going into winter.

What are your biggest concerns as we head into winter?

Word cloud

Figure 3: Word cloud showing key words used by respondents related to how could an employer and workplace show they are inclusive of people affected by neurological conditions.

Thematic analysis

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

Theme 1: Worsening of health conditions.

- Affected by cold and pain.
- Managing symptoms.

- Lack of sleep.

Theme 2: Infections.

- COVID and flu infections.
- Getting vaccines.

Theme 3: Access to healthcare and social care.

- Timely access to healthcare services.
- Strain on NHS.
- Strikes.
- Shortage of carers.

Theme 4: Financial concerns.

- Affording the bills
- Affording food
- Other financial concerns

Theme 5: Mobility.

- Accidents
- Going out
- Transport

Theme 6: Mental health and isolation

Theme 7: Weather, climate, and politics

- Climate change and weather-induced situations
- War and political situations

Theme 8: No concerns

Theme 1: Worsening of health conditions.

Respondents reported that they were concerned the coldness of winter would exacerbate their symptoms and cause more pain. There were also concerns about how to manage those symptoms and how the cold might affect their sleep.

Affected by cold and pain.

"My main concern is how my condition, together with my osteoarthritis, will cope with very cold temperatures if we have them, as I try not to put the heating on if I am on my own at home during the day."

"My circulation is very impaired and I get cold very quickly. As I cannot walk and use a wheelchair, it means whenever I am outside I am at risk of getting very cold, which takes hours to recover from."

"I can't cope with the cold/damp - my body just rebels."

"The cold weather as it cold enough now its causing my body and head to hurt a lot."

"Pain and movement become progressively worse with cold."

Managing symptoms.

"Keeping my condition stable."

"Controlling both conditions especially at night."

Lack of sleep.

"I wake at 2.30 to 3.30 am and get up. I must keep warm for hours before I can justify putting the heating on."

Theme 2: Infections.

The respondents also expressed concerns about getting infected by COVID or flu, and were worried about the availability of vaccines.

COVID and flu infections.

"I know that if I am unwell I wouldn't go to a&e as there will likely be high numbers of people there with flu or Covid."

"Flu/sickness as they affect me badly."

" I wish I saw more masks being worn!!! Especially in healthcare settings."

"Contracting Covid, at hospital especially due to lack of regulations to protect patients and healthcare workers."

Getting vaccines

"Availability of vaccines and healthcare."

"I have been told I'm not classed as needing the flu or covid vaccine and I have just had covid and was very poorly don't want to catch anything else."

Theme 3: Access to healthcare and social care

The respondents expressed concerns about their access to healthcare and social care during winter, mainly about getting timely access to healthcare services such as availability of ambulances and treatments, given the long waiting list and frequent cancellations. Related to this, they were also worried about the strain on the NHS during winter and how strikes & a shortage of carers may affect their access to both healthcare or social care.

Timely access to healthcare services

"…not receiving swift treatment and support (as someone who is vulnerable due to being immunosuppressed), because of the lack of GPs, nurses, hospital doctors, consultants etc. As more of the NHS is privatised, there's a danger that more emphasis is placed on profit than caring for patients."

"Lack of immediate care and advice. Lack of ambulances to reach me in a rural location."

"Getting to see a consultant, getting treatment for lymphedema, getting treatment for bursitis."

"The NHS will be busy so waiting lists will get even longer."

"Lack of beds if I need to be admitted to hospital."

Strain on NHS

"Community Neuro physio. & Neuro O.T. off work with sickness or family needs - scary witnessing the stress & lack of resources & skill mix or neurology knowledge impact on already thin on the ground staff - I feel concerned for myself & my husband as inadequate support is available."

"That my local hospital won't be able to cope."

"Strain on an underfunded NHS."

Strikes

"More industrial action by junior doctors and consultants."

"If I need to see a doctor how will the strikes effect me."

"If there is any strikes that will make the situation worse though I understand their reasons for striking."

Shortage of carers

"Also awaiting social service assessment for a carer to take me out socially, very long wait again. Fed up of waiting. Just sorting myself out!"

"Shortage of carers."

Theme 4: Financial concerns.

The respondents were concerned about their financial ability to afford heating, food and other necessities for living due to the cost-of-living crisis.

Affording the bills.

"Cold weather little money to heat."

"Being able to pay bills."

"Heating to a constant temperature 24 hours is too expensive."

"I'm dreading the whole energy bills game again. As someone on legacy benefits, I don't qualify for all the uplifts/cost of living handouts - this is discrimination on a wide scale. If wealthy older people can get and keep their winter warmth payment, why can't those on contributions-based ESA and/or PIP who just creep over the savings threshold for UC get anything other than the occasional grudging handout? I live alone, I don't have a partner or family to bear the cost burden of rent, bills etc. Single disabled folk - where's the help for us if we don't tick the right boxes?"

Affording food.

"Affording good quality food & preparing & cooking it."

"Price of food…."

"Being able to afford stock up food/supplies if we get snowed in & keep up with the bills."

Other financial concerns.

"Financial institutions stealing all our money. Pension companies stealing on average 50% of pension pots. Mortgage companies charging huge interest rates to disabled people…"

Theme 5: Mobility.

Another theme that emerged was related to mobility. Due to the cold weather and slippery conditions, respondents were worried about going out or falling over, as well as getting transport from one place to another given the darkness and weather conditions.

Accidents

"Slippery conditions on pavements and footpaths."

"Falls outside."

"Snow and ice as I'm very unbalanced physically."

Going out

"Continuing to be enthusiastic to go for a walk with my carer and neurophysio and to practice in my garden."

"The dark evenings and not being able to go out when the weathers too bad."

"If we have a bad winter I will be housebound."

Transport

"Accessing treatment as the hospital is quite far away and public transport isn't good."

"Travelling across the humber bridge to see the neuro in bad weather the bridge closes, I couldn't cope with the 50+ mile further travel around the humber by road."

"I have to have hospital transport to get to appts - this usually takes a whole day of sitting and waiting which is difficult when I cannot use toilet and have to dehydrate."

Theme 6: Mental health and isolation

The respondents were concerned about their mental health due to the isolation that winter can bring, as they will be housebound and do not go out often.

"I also find the dark mornings and evenings difficult on my mental health."

"Dark, depressive thoughts."

"The dark days really affect my seasonal affective disorder which is not great when my depression is also very bad"

"Being isolated at home as the cold makes my symptoms worse."

Theme 7: Weather, climate and politics.

Concerns over weather-induced situations, climate change and politics were cited by the respondents too.

Climate change and weather-induced situations.

"The climate emergency."

"Climate change."

"Any problems which may occur with services of gas, electric, water, etc."

"power outages."

War and political situations.

"The rising threat of a Socialist government."

"Ukraine war."

Theme 8: No concerns

A number of respondents have also expressed that they had no concerns at all.

"I don't have any concerns, as the summer months affect me more."

"None for the moment"

"No major worries to be honest with you…"

Will your care, support, or information needs change in the next 6 months?

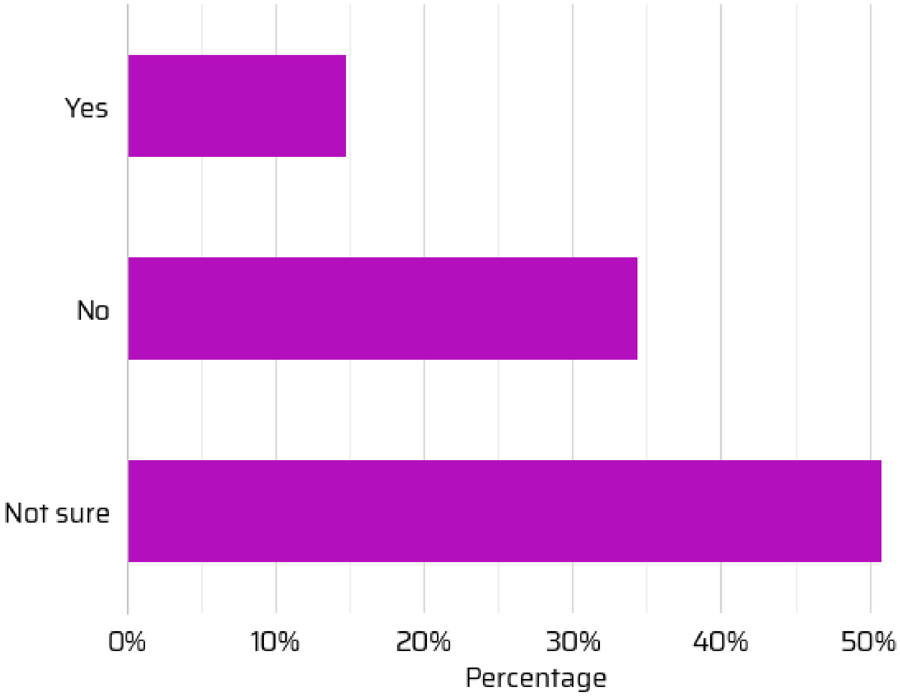


Figure 4 Will your care, support or information needs in the next 6 months.

Table 2 Will your care, support or information needs in the next 6 months.

Response	Respondents	Percentage
Yes	101	14.74
No	236	34.45
Not sure	348	50.8

How the care support or information that you receive needs to change?

Word cloud

Figure 3: A word cloud showing keywords used by respondents related how the care support or information that they receive needs to change.

Thematic analysis

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

Theme 1: Improve the healthcare system.

- Better access to treatments, appointments, and test results.
- More testing.

- More support and understanding from the GP.
- More physiotherapy.
- Multidisciplinary support.

Theme 2: Support with managing conditions.

Theme 3: Improve the information given.

- More information on follow-up plan.
- More explanation of condition and test results.
- Signposting to other sources of help and information.

Theme 4: Awareness and training.

- Better understanding of neurological conditions.
- Training for health professionals or support workers.
- Recognition and awareness of conditions.

Theme 5: Support outside healthcare system.

- Long-term/post-surgery support.
- Mental health support.
- Financial support.
- Help with moving.
- Career support.
- Social care.
- Local community support.
- Facilities.

Theme 6: "Not sure".

Theme 1: Improve the healthcare system.

The first theme that emerged was suggestions for how the healthcare system can be improved. This includes ensuring better access to treatments, appointments and test results, more testing, more support from GP, more physiotherapy and having multidisciplinary teams in treating patients.

Better access to treatments, appointments and test results.

"Better access to Neurological Cons & Tel Cons or appt, when condition or symptoms feel out of control, rather than wait for future appt, when dates not available for at least 3mths."

"Need to have Face to face appointments as opposed to telephone appointments."

"Results from routine blood check are awaited."

"Better management of waiting lists"

"I find it very difficult to get anybody to call me back when I have left messages on their answerphone."

More support and understanding from the GP.

"Better understanding in primary care."

"My GP refuses to review my epilepsy and migraine - no blood samples taken to check if medication is having detrimental effects."

More physiotherapy.

"I need help with physiotherapy and mobility aids"

"Appropriate physio and more reliable personal care."

" I need a lot more physiotherapy before I am able to walk to the bus stop even one way, but I have been told that I already had more sessions than they usually offer."

Multidisciplinary support

"Access to telemedicine with multi-disciplinary teams would be a boon. We need a centre of excellence for people with Mal de Debarquement Syndrome in the UK."

"Better communication between medical disciplinaries."

"All various departments within NHS and private companies who manage certain aspects of my health issues on behalf of NHS need to start sharing of information and treating me as a whole and not individual parts when there are clear overlaps."

Theme 2: Support with managing conditions

The respondents have also expressed that it is important to have more support and help with how they can manage their conditions and pain.

"I need help to understand the new symptoms and what I can do to try and relieve them."

"Offering support in adapting to changes rather than bundling symptoms into a psychological category."

"How to reduce or mitigate changes?"

"My pain management is not good. I need help to make it change."

Theme 3: Improve the information given.

The respondents reported that they need more information on follow-up plans, their conditions, as well as other sources of help or support they can get.

More information on follow-up plan

"I had very little (none) advice or care following my diagnosis, no referral to occupational health or specialist nurses. The consultant, and I appreciate that he is a busy man, gave us very little information. It was only through googling the condition that we discovered the Ataxia Society and, through their information, managed to get a referral to the specialist unit at Sheffield Hospital."

"I'm moving to another part of the country, so not sure if my notes will keep up with me"

"I received a diagnosis and that was it. No plan. No further info."

More explanation of condition and test results

"A little time needs to be spent with the patient explaining. And answering questions. Giving a grounding of the condition. Otherwise its bewildering."

"Would be nice to know outcome of MRIscan."

"Dialogue with an expert to ask questions."

Signposting to other sources of help and information

"However, one glaring omission….is the lack of any information (a simple leaflet would do) at the point of discharge about relevant support organisations/groups. It is left to the individual, who is invariably traumatised and coping with massive life changes, to seek these out."

"Not sure what might be available to help."

"Pointing in the direction of local or national help and information."

Theme 4: Awareness and training

It was also pointed out that there is a lack of awareness of neurological conditions, and that there is a need for more research, training, and recognitions.

Better understanding of neurological conditions

"Listening to my history & taking it in to account."

"Better communication, not being treated as another patient, but a person with its own life and needs and struggles specific to me."

"Need to have more consistency /understanding patients needs."

Training for health professionals or support workers

"It would be interesting to find out more and for medical and paramedical services to know more (or something) about CMT."

"Those providing me with medical care need to receive training on ME, especially the needs of the severely affected. I am currently at risk of harm in every encounter."

“More information for doctors, who usually have no idea what you are talking about! Which is why I was not diagnosed until 2012, but had been going to the GP since 1998.”

Recognition and awareness of conditions.

“Acknowledgment that if certain symptoms aren’t addressed they exacerbate others.”

“Increased awareness of condition.”

“More information about the condition so more people can understand it.”

Theme 5: Support outside healthcare system

Given the debilitating symptoms of neurological conditions, a range of subthemes related to support outside the healthcare system have emerged. These include long-term support post-surgery, mental health support, financial support, help with moving, help with career, social care, local community support, and others.

Long-term/post-surgery support.

“More support after surgery.”

“I’m just about to have my last MRI scan as it’s the 10 year anniversary since my surgery . I feel I will now be unsupported.”

“As balance and coordination continues to deteriorate, will need more support with issues requiring mobility.”

Mental health support

“My mood will be lower i will need better support mentally.”

“I’m feeling emotionally lost, anxious and fearful, with no support offered via NHS, paying for private psychotherapy support.”

“My condition is deteriorating therefore my needs increase including psychological support.”

Financial support

"I have a treatment package suggested by a consultant, but no hope of accessing it unless I find the money to fund it myself."

"I need a lot more money to support private medical treatment for another condition I have for which I cannot get safe, reliable NHS treatment."

"I've waited a year for my PIP review assessment and still have no new award as yet. I'm so stressed out about how I am going to manage to continue to live alone in a privately rented property."

Help with moving.

"Need help in moving to a more competent area for family help!!"

"HELP IN HOME AND TO MOVE TO A SUPPORTIVE AREA IN KENT!!"

Career support

"Hoping to return to work although not without the support of a Neuropsychologist. Once I've had some tests & help I'm hoping to find a new career."

Social care

"I may need more hours from my care providers, a cost which already takes almost 80% of my State pension."
"Have not been able to recruit a carer for last 2 years. Carers are poorly paid compared to other jobs & hold a lot of responsibility & this puts them off."

"A lot more government funding is needed to ensure social care services are adequately funded as they are all short staffed, underfunded, and have long waiting lists."

"As the weather turns colder, I will need more help with dressing (more clothes) which in itself means more help toileting. Cooking hot meals."

"Likely to need more night time care."

Local community support

"I am fortunate with the care from my consultants to whom I travel to see but support and care and support locally for other needs is lacking."

"more online groups and peer support."

Facilities

"Will need heating on more suffer greatly by cold weather".

"Need pools around more."

Theme 6: "Not sure"

Some respondents have indicated that as their conditions are unpredictable, it was hard for them to know what form of support or care they would need.

"My illness is unpredictable, so I don't know."

"My damaged ankle is getting worse and I don't know how things will develop in the next months."

"Depends how my condition progression."

Quality of life

Impact on quality of life.

Neurological conditions affect all aspects of a person's life, and you shared to what extent your lives were impacted and how.

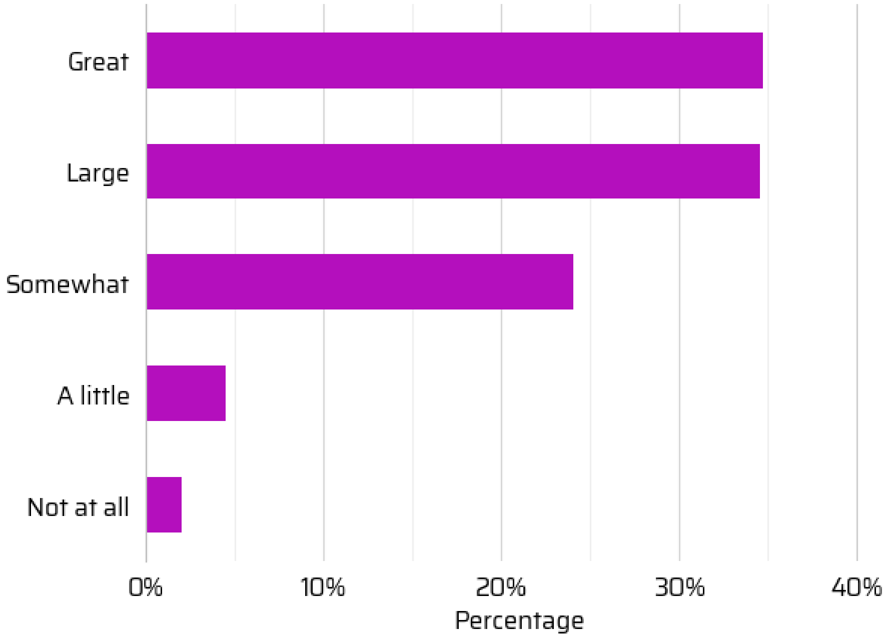


Figure 5: Overall impact on quality of life.

Table 3: Overall impact on quality of life.

Impact	Respondents	Percentage
Great	238	34.74
Large	237	34.6
Somewhat	165	24.09
A little	31	4.53
Not at all	14	2.04

Impact on quality of life: with vs without multiple neurological conditions.

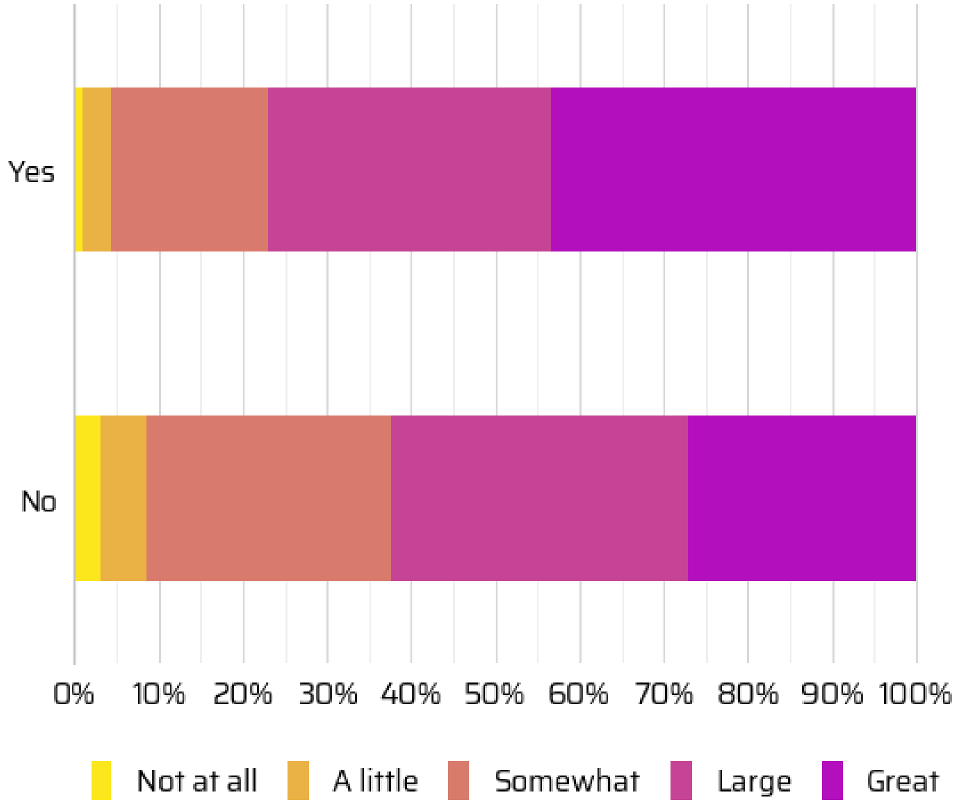


Figure 6 Impact on quality of life among people with vs without multiple neurological conditions.

Table 4 Impact on quality of life among people with vs without multiple neurological conditions.

Multiple neurological conditions	**Impact**	**Respondents**	**Percentage**
Yes	Great	140	43.34
	Large	109	33.75
	Somewhat	60	18.58
	A little	11	3.41
	Not at all	3	0.93
No	Great	98	27.07

	Large	128	35.36
	Somewhat	105	29.01
	A little	20	5.52
	Not at all	11	3.04

Impact on quality of life: with vs without co-occurring non-neurological condition.

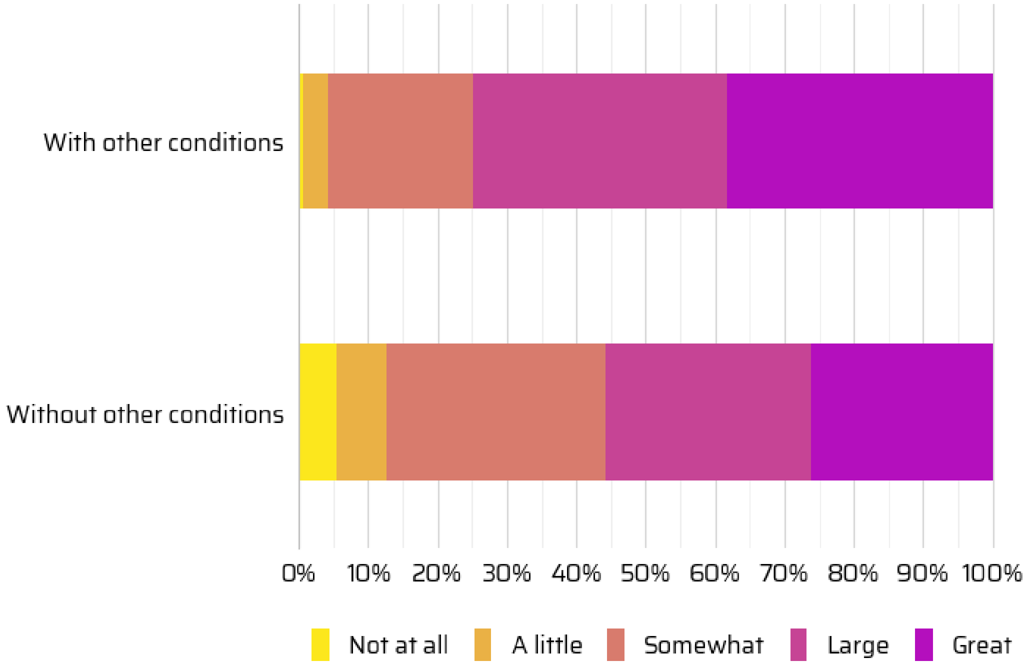


Figure 7 Impact on quality of life among people with vs without co-occurring non-neurological conditions.

Table 5 Impact on quality of life among people with vs without co-occurring non-neurological conditions.

Co-occurring conditions	**Impact**	**Respondents**	**Percentage**
With other conditions	Great	186	38.27
	Large	178	36.63
	Somewhat	102	20.99

	A little	17	3.5
	Not at all	3	0.62
Without other conditions	Great	52	26.13
	Large	59	29.65
	Somewhat	63	31.66
	A little	14	7.04
	Not at all	11	5.53

Impact on quality of life: age groups.

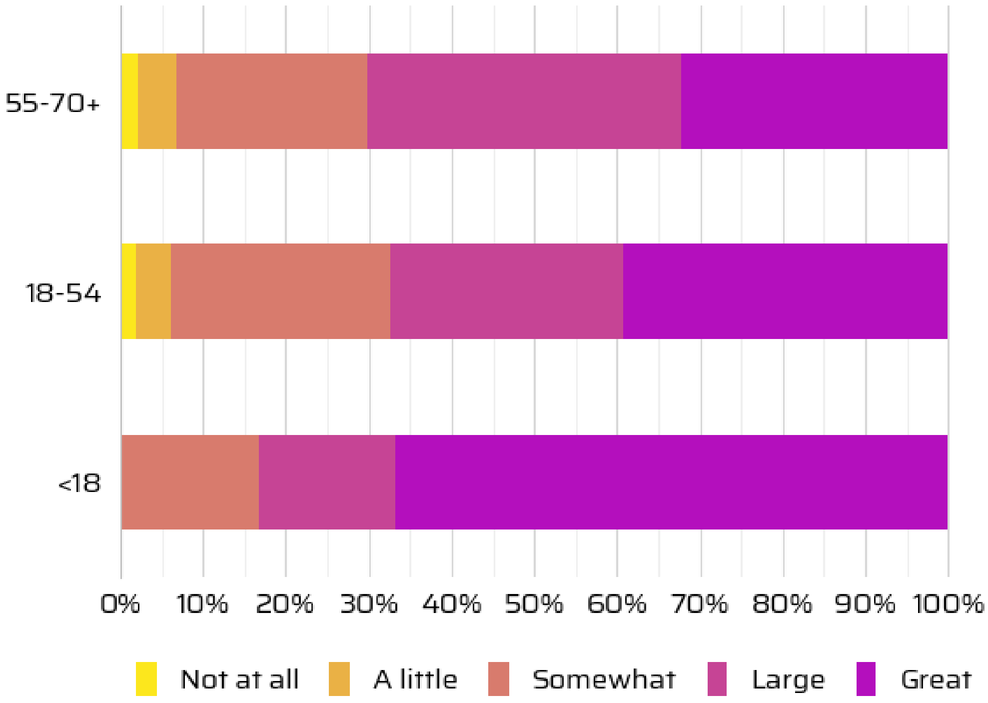


Figure 8 Impact on quality of life among people in different age groups.

Table 6 Impact on quality of life among people in different age groups.

Age	Impact	Respondents	Percentage
55-70+	Great	151	32.26
	Large	177	37.82
	Somewhat	108	23.08

	A little	22	4.7
	Not at all	10	2.14
18-54	Great	83	39.34
	Large	59	27.96
	Somewhat	56	26.54
	A little	9	4.27
	Not at all	4	1.9
<18	Great	4	66.67
	Large	1	16.67
	Somewhat	1	16.67
	A little	0	0.0
	Not at all	0	0.0

Impact on quality of life: gender.

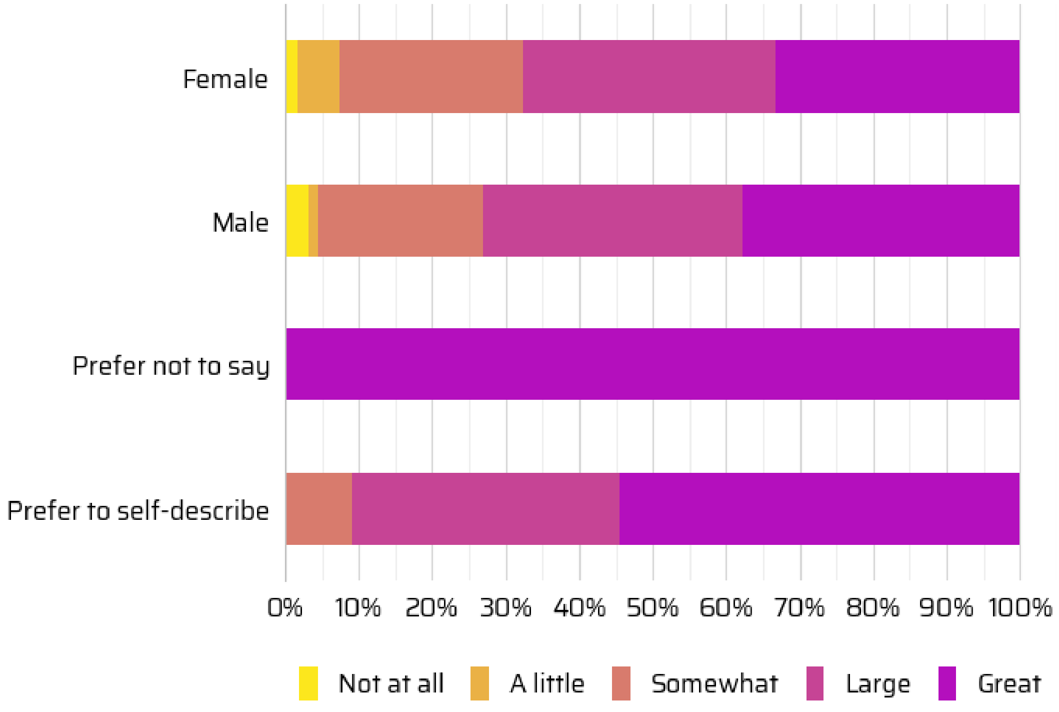


Figure 9 Impact on quality of life among people in different genders.

Table 7 Impact on quality of life among people in different genders.

Gender	Impact	Respondents	Percentage
Female	Great	172	33.27
	Large	178	34.43
	Somewhat	129	24.95
	A little	29	5.61
	Not at all	9	1.74
Male	Great	59	37.82
	Large	55	35.26
	Somewhat	35	22.44
	A little	2	1.28
	Not at all	5	3.21
Prefer not to say	Great	1	100.0
	Large	0	0.0
	Somewhat	0	0.0
	A little	0	0.0
	Not at all	0	0.0
Prefer to self-describe	Great	6	54.55
	Large	4	36.36
	Somewhat	1	9.09
	A little	0	0.0
	Not at all	0	0.0

Impact on quality of life: employment status.

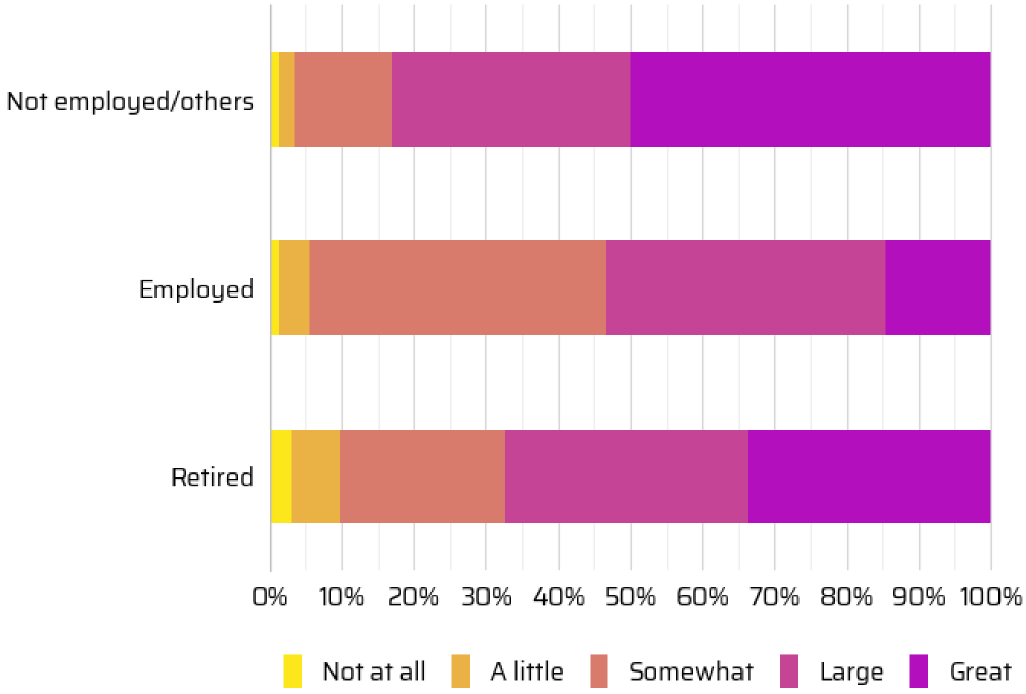


Figure 10 Impact on quality of life among people in different employment status.

Table 8 Impact on quality of life among people in different employment status.

Employment status	Impact	Respondents	Percentage
Not employed/others	Great	117	50.0
	Large	77	32.91
	Somewhat	32	13.68
	A little	5	2.14
	Not at all	3	1.28
Employed	Great	24	14.72
	Large	63	38.65
	Somewhat	67	41.1
	A little	7	4.29
	Not at all	2	1.23

Retired	Great	97	33.68
	Large	97	33.68
	Somewhat	66	22.92
	A little	19	6.6
	Not at all	9	3.12

Impact on quality of life: with vs without dependents.

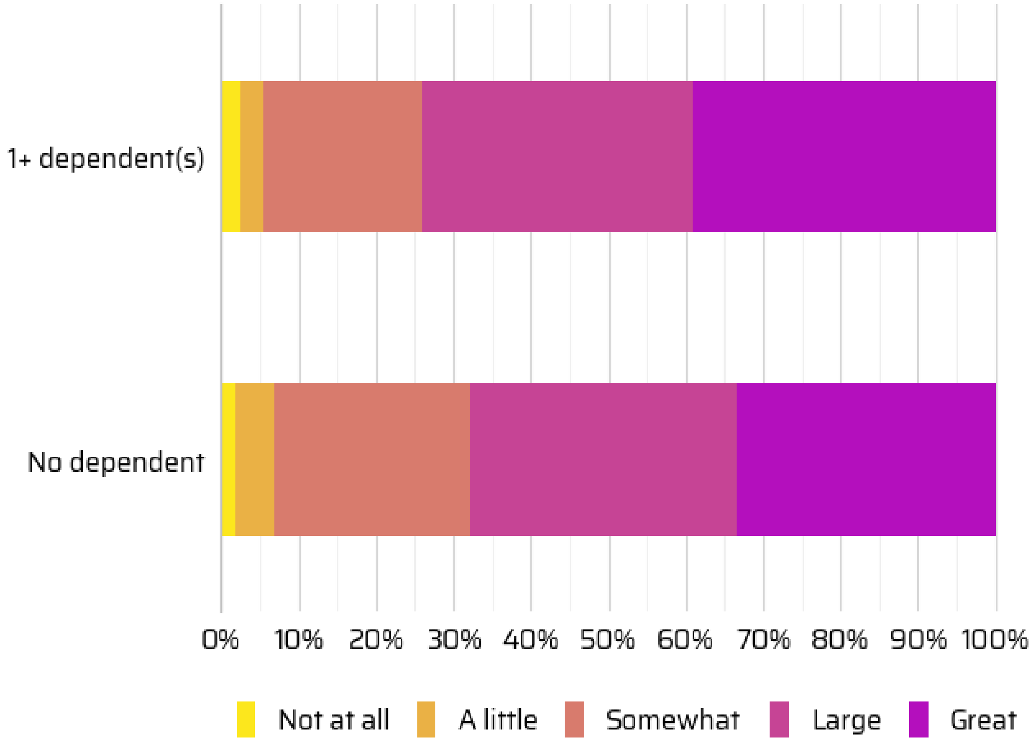


Figure 11 Impact on quality of life among people with vs without dependents.

Table 9 Impact on quality of life among people with vs without dependents.

Number of dependents	**Impact**	**Respondents**	**Percentage**
1+ dependent(s)	Great	65	39.16
	Large	58	34.94
	Somewhat	34	20.48
	A little	5	3.01

	Not at all	4	2.41
No dependent	Great	173	33.33
	Large	179	34.49
	Somewhat	131	25.24
	A little	26	5.01
	Not at all	10	1.93

Impact on quality of life: extent of mental health needs met or not.

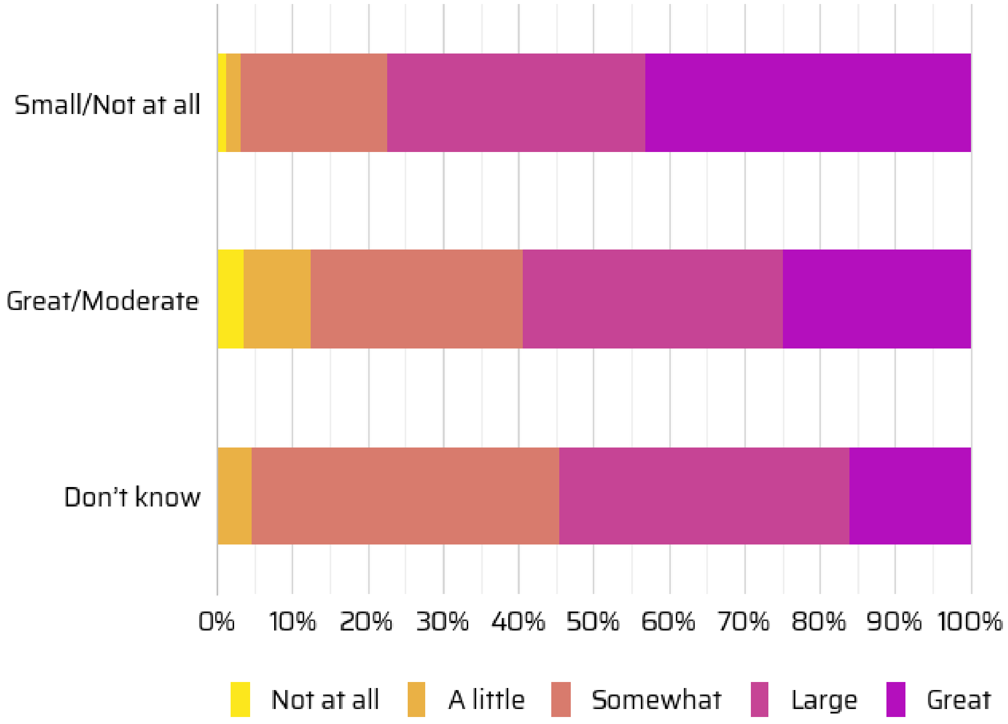


Figure 12 Impact on quality of life among people with different extent of mental health needs met.

Table 10 Impact on quality of life among people with different extent of mental health needs met.

Needs met	Impact	Respondents	Percentage
Small/Not at all	Great	169	43.11
	Large	134	34.18
	Somewhat	77	19.64
	A little	7	1.79

	Not at all	5	1.28
Great/Moderate	Great	62	24.9
	Large	86	34.54
	Somewhat	70	28.11
	A little	22	8.84
	Not at all	9	3.61
Don't know	Great	7	15.91
	Large	17	38.64
	Somewhat	18	40.91
	A little	2	4.55
	Not at all	0	0.0

How has your quality of life been impacted by your neurological condition(s)?

****Trigger warning****

Please note this report contains material of a highly sensitive nature including references to suicide and death that may be triggering for some individuals.

Word cloud

Figure 13: Word cloud showing key words used by respondents related to how has your quality of life been impacted by your neurological condition (s).

Thematic analysis

Thematic analysis was conducted for responses to the question. The following themes emerged:

Theme 1: Disruptions to daily physical and cognitive functions.

- Activities of daily living (ADL) impairment.
- Dexterity.
- Hearing loss.
- Sleep problems.
- Reduced cognitive abilities.

- Incontinence.
- Eating and swallowing food.
- Poor eyesight.
- Hypersensitivity to noise.
- Breathing issues.
- Comorbid conditions.

Theme 2: Mobility and accessibility

- Unable to drive.
- Movement, balancing, and standing up.
- Housebound or hard to go out.
- Lose access to many places.

Theme 3: Pain and discomfort.

- “I live in constant pain”.
- Fatigue and exhaustion.
- Nausea, dizziness, and headache.

Theme 4: The opportunity costs of having neurological conditions.

Theme 5: Identity and mental health.

- Change in identity.
- Stolen joy.
- Lack of life fulfilment.
- Psychological distress.
- Dealing with uncertainties and changes.
- Loneliness.
- Lost confidence.
- Feeling trapped for being disabled.

Theme 6: Financial and economic impact.

Theme 7: Interpersonal relationships.

- Reduced capability to socialise.
- Become reliant on others.
- Mistreatment and misunderstanding.

Theme 8: Treatment and side effects.

Theme 9: Lack of support.

- Lack of treatment support.
- Lack of governmental support.

Theme 10: Living space.

- Housing conditions.
- Care home.
- Homelessness.

Theme 11: Positive outlook.

Theme 1: Disruptions to daily physical and cognitive functions

The survey respondents reported that their neurological conditions impacted their quality of life through disruptions to their daily physical and cognitive functions. These include impairment of their daily living activities, challenges in their dexterity, hearing loss, sleep problems, reduced cognitive abilities, incontinence, eating and swallowing food, poor eyesight, hypersensitivity to noise, breathing issues and having comorbid conditions.

Activities of daily living (ADL) impairment.

> "No showers anymore, no stopping, standing and chatting as I walk in the park. No queueing in shops. I do my cooking whilst sitting on a stool along with ironing, gardening etc. I sit in the floor to hoover and sort out the washing. I have moved from yoga to chair yoga. There's more but I'll stop there."

> "Even every day tasks such as showering, eating, talking exhaust me. I want to do normal things, prepare a meal, help with housework, socialise, go for a walk, be able to plan a day of doing something, anything."

> "Everyday living, from washing, dressing, preparing meals, laundry & household chores, shopping, social activities….."

"It affects all aspects of my life, walking, moving interactions with others, personal care, increased fatigue levels, ability to make food and clean my house and clothes."

Dexterity.

"Hand writing and playing piano....very difficult."

"Find it difficult to use a computer."

"I can type only with my left hand."

"I used to play musical instruments and can no longer, my handshakes..."

Hearing loss.

"Hearing loss, pain, tinnitus...."

Sleep problems.

" Sleep problems and vivid unpleasant dreams."

"The symptoms impact me every day. My sleep is impacted and that exacerbates my energy levels every day."

" My sleep is poor due to neurological pain."

Reduced cognitive abilities.

"I am also (my term) 'cognitively challenged' and can experience fatigue, lapses in concentration, problems with multitasking etc."

"I have difficulty in focusing so can no longer read."

"I can't recognise the names of objects, retain information or understand questions."

Incontinence.

"Bladder & bowel problems."

"I need the toilet every time I stand up and don't always make it and I take an awful long time to do simple tasks."

"Having cauda equina means I don't have control over my bowel."

Eating and swallowing food.

"Because I have difficulty swallowing this provokes bad coughing fits so I no longer eat in restaurants or visit pubs, bars, etc."

"Swallow is affected and is scary."

"I'm unable to chew so live on a liquid diet."

Poor eyesight

"Eye condition makes some recognitions (eg coins, shelf labels) quite difficult."

"Peripheral vision loss/optic nerve atrophy."

"I have double vision so I cannot read either."

"I can't read text on paper very well anymore. I need the backlit text from a screen."

Hypersensitivity to noise

"I am hypersensitive to noise any sort of noise, going to a supermarket is a real struggle so can only manage 10-15mins at the most."

Breathing issues

"I want to be near my oxygen when I have cluster attacks."

Comorbid conditions

"It gets difficult if for example I catch cold/flu."

"Low blood pressure/orthostatic hypotension."

Theme 2: Mobility and accessibility

Having neurological conditions rendered respondents with challenges in mobility and accessibility. They may become unable to drive, having problems walking or standing up, leading to them being housebound or finding it hard to go out and losing access to many places.

Unable to drive.

“Lost my driving license.”

“I am no longer able to drive so I am reliant on others for lifts if I go away from the area immediately around the house.”

Movement, balancing, and standing up.

“I cannot walk as I used to. I cannot use stairs easily. I have to use walking sticks.”

“I have severely reduced mobility and can only go out in a wheelchair.”

“I have difficulty with my balance and coordination.”

“I cannot walk, only shuffle while holding a grab rail.”

Housebound or hard to go out.

“Gone from being active, working part time and articulate to house bound.”

“Almost housebound, unable to stand for more than seconds.”

“Cannot leave home without mobility scooter or wheelchair.”

Lose access to many places.

“Cannot use art galleries or similar without a wheelchair, Any venue where the audience leave en masse is difficult.”

“Limited access to commercial and social venues.”

“Not having accessibility due to my hearing loss - so many places are not hearing aware. It’s draining.”

“I can’t physically participate in most activities. Poor access to many places as well.”

Theme 3: Pain and discomfort.

Due to their neurological conditions, the respondents’ quality of life was also affected by pain and discomfort.

“I live in constant pain”

“I live in Constant pain, it’s very difficult to cope with as I need to work and using pain meds make that difficult so most of the time I can’t take any.”

“Every hour of every day is different due to pain and if I happen to make the effort to go out, I pay for it for the next 2 days due to lack of energy and excessive pain.”

“Pain affects all aspects of my life and my ability to lead the life I want.”

Fatigue and exhaustion.

“Pain makes me tired - pain and tiredness stop me doing things.”

“The condition makes me very tired. Everyday tasks are very difficult.”

“Fatigue is exacerbated by the hard work it takes to hear, see and read, process information and words, process verbal responses, plan, work, travel, think, move, write, shop, clean etc. Basically everything, everyday is a challenge. It is exhausting just to exist.”

Nausea, dizziness, and headache.

“I suffer with balance and dizziness even though I now use a stick for support I don’t really like going to far from home.”

“....headaches, dizziness and disorientation and sickness.”

“Migraine once a week has a large impact. In some ways more of a concern than epilepsy.”

Theme 4: The opportunity costs of having neurological conditions.

Having to control and manage the symptoms of neurological conditions also means the respondents need to plan a lot in advance. Consequently, they cannot achieve much what they would like due to the time and energy spent on managing and controlling those symptoms.

"I have to pace myself so carefully that there is little scope for me to do anything except care for my basic needs."

"Can't do what I want when I want. Need to plan, no spontaneous activity, even going out of the house."

"I can't go out, i feel like I am always stuck in limbo always waiting for something to happen - such as appointments, waiting for medication, waiting for results. I just feel I can't move forward as I am always dealing with symptoms from my neurological conditions. I am always chasing things up."

"Having to go back to bed again so losing time to do things."

"I have to consider how everything I do will impact on my condition and pace myself very carefully. Even when I do this, my condition still deteriorates which I find difficult to cope with."

Theme 5: Identity and mental health.

Respondents told us that having a neurological condition(s) changes their sense of identity as they realise that they are not the people they used to be. They cannot enjoy the things they used to enjoy doing, feeling a lack of fulfilment in life, and consequently their mental health has been negatively affected.

Having a neurological condition(s) means that people must deal with uncertainties and changes due to their fluctuating condition(s). Some respondents as a consequence of being disabled due to their neurological condition(s) expressed a feeling of being trapped. This all can impact their self-esteem and confidence, while also leaving them feeling isolated and invisible.

Change in identity.

"Because I have been left with a changed personality… I'm not the person I use to be."

“I have changed completely, friends have gone, I look ok but inside I am scared all the time.”

“I have had to learn a totally new way of living.”

“My life has changed since my diagnosis its changed me as a person.”

” I have struggled coming to terms with the changes, being on benefits especially as am used to being my main breadwinner & as a self sufficient person.”

Stolen joy.

“Having done yoga for 50 years, I’m now finding more problems with it.”

“I can no longer enjoy the things I used to do, like walking, hiking, rambling, keep fit.”

“I’m unable to take part in the hobbies I wish too as they’re too physical for me now.”

“my hobbies of Hill walking, traveling across country in vehicles, martial arts & gardening are no longer feasible.”

Lack of life fulfilment.

“I don’t have the ‘inputs’ to allow both sustenance of intellectual capacity and best (self-) management of ‘physical’/wellbeing balance.”

“It is stopping me from living my life.”

Psychological distress.

“Waiting over a year to see a Neuropsychologist making me extremely depressed and hopeless.”

“If the physical pain wasn’t enough to make me want to die, the sheer brick wall, complacent attitude, in 2023, of government to ignore the very existence of neurologically disabled people, even the departments that specifically deal with disabilities, is shocking and depressing and [it] makes you want to crawl [into] a hole and die….”

"Most of my friends have disappeared and those that are left are getting fed up of me not being able to do fun things and being very limited so they are also slowly withdrawing from me and soon I'll be left with no one. This is having a major impact on my mental health and I wish I no longer existed."

"one time I hit the side of my head on the sink on the way down and gave myself a black eye, I was in so much pain for days after that happened, it scared me so much, I feel depessed and emotionally drained from not getting the help and support I need."

Dealing with uncertainty and changes.

"Not knowing when your next treatment is going to be is very upsetting, it all gets you down."

"Anxiety at what the future might hold following an admission to hospital where the only available bed was on a locked dementia ward. I dread having to be admitted to my local hospital in the future and will refuse to go."

"Stops me feeling to think ahead confident as I'm unsure what my condition will be like."

"Fear of going out unprepared for any seizures."

Loneliness.

"Friends & family not interested in my lived experience. Its very lonely."

"I have become very isolated. I doesn't help that I keep thinking I have been a nurse for more that 30 years and really liked worked in the profession"

"I have no one,never go out."

"I feel forlorn. Ignored."

"Very isolating condition."

Lost confidence.

"I have lost so much confidence, I rarely go out on my own."

"I'm embarrassed by the dystonia facial expressions in public."

"I feel less confident in being able to cope with what lies ahead."

" I cannot out my own socks and shoes on or transfer to the shower without my husband's help. Now of this is great for self esteem! My entire life is impacted."

"Feelings of little worth."

Feeling trapped for being disabled.

"I find my condition difficult to manage as it changes so much. This means that I am severely limited in what I can do and where I can go."

"Can't work or drive. Am in wheelchair and live alone. Very restricted to what I can do"

"I'm limited in the amount that i can do. i can't cook any more or read a book. i can't focus for long. i have had to accept these limitations but they do cause me to have low mood often."

"50% loss of function in daily living since 2013"

Theme 6: Financial and economic impact

Having neurological conditions have also impacted the respondents' financial and economic circumstances.

"I'm in the process of further reducing the hours that I work as it's too much currently."

" Now that I can't function properly any longer I can't even get a part-time job, there is no support whatsoever."

"but Mal de Debarquement Syndrome robbed me of my career, my ability to study for a PhD, my ability to fulfil family roles, my financial independence and my trust in doctors."

"I'm unable to do the job I want to, this means I earn less money, which impacts on the quality of my life."

"I am too ill to work."

"I used to earn ~£75k/year before my accident. Now I'm just getting benefits."

"Hard to plan for future, no money to live on or pay rent."

Theme 7: Interpersonal relationships

The respondents reported that their conditions affected their interpersonal relationships. These include having a reduced capability to socialise, becoming more reliant on others, or being subjected to mistreatment and misunderstanding.

Reduced capability to socialise.

"I don't socialize, I'm not going to college as it doesn't meet my needs, I don't have friends, I can't go out by myself."

"I can't stand but for a few minutes, so I avoid people if I see them when I'm out, I stop going to occasions where I no I'll have to stand."

" I have become very reclusive and anti-social as I do not feel I can go anywhere and I do not trust anyone."

"The pressure and pain causes me to not want to do anything and just stay away and hide."

" My peer group are all busy with work & social life & my disabilities mean socialising independently is not an option."

Become reliant on others.

"I am fully dependent on others for all aspects of care."

"I rely on my partner or others. I've lost some of my independence."

"Rely more on family to drive me places."

"I require full time care from my parents, I will never have any independence."

"I am totally reliant on other people. I cannot do things when I want or how I want. I feel I am a nuisance."

Mistreatment and misunderstanding.

"I have been bullied and harassed in work due to my condition - special equipment tampered with."

"People talk over me as I struggle to get my broken words out."

"My condition is a mostly hidden one, if I try to explain people say well! You look ok.."

"My Parkinson's sometimes makes me anxious and very tired, this causes difficulties with close by friends and relatives who cannot see or understand the day to day difficulties that you are dealing with."

"I work at a school as a Teaching Assistant and I have not been treated fairly."

Theme 8: Treatment and side effects

Another theme that emerged was that the respondents have to receive treatments for their conditions which may induce unwanted circumstances such as side effects. On the other hand, losing access to treatments may cause the respondents discomfort and pain too.

"My medication gives me brain fog."

"The medicines used to treat the condition have given many difficult to manage side-effects, [including] tremor."

"Eating is difficult whether I use brace or not and limits social eating;"

"When I was being given botox injections every 13 weeks my symptoms & pain were well managed but since the pandemic I have been waiting on average 20 weeks between injections. This has led to much more pain and discomfort and worse tremor than usual."

Theme 9: Lack of support

It was also reported that there was a lack of healthcare and treatment support as well as governmental support.

Lack of treatment support

"Lack of neurology specialists or carers trained in neurology awareness or cognitive organic training."

"The NHS denied me access to medical care for literally decades."

"I'm only 19 but the NHS has swept me under the rug and left me to suffer alone."

"I have only seen the neurologist once in that time and I have been given no treatment. I have only been referred to a psychologist and I'm still on a waiting list for an assessment."

Lack of governmental support

"I have to deal with the DWP, who even though they lost a landmark case to the RNIB for their shocking lack of accessible copies I am now having to fight with the help of the RNIB because their review form isn't available in an accessible format, and it just makes you want to die because everything hurts, everything is so goddamn difficult and those that specialise in disabilities (DWP PIP team or my councils adult social care team) do not accommodate you if you cannot see, let alone cannot travel."

" Authorities such as my dealing with my local authorities are very difficult. No allowance made for my condition. People sent to carry out jobs in my home without being made aware of my condition."

Theme 10: Living space.

A theme related to living space has also emerged, where respondents were in inappropriate housing conditions, had to live in a care home, or had become homeless due to their neurological conditions.

Housing conditions

"My housing is not entirely appropriate for my needs."

"I have to plan ahead, I live in a property that is unsuitable for my need."

"I am disabled, weak, walk with crutches for short distances but live in a 2nd floor flat with no lift & cannot live independently."

Care home

"I now unfortunately live in a care home."

Homelessness

"Due to the lack of information, care, support, and treatment for the first 9 years following my ABI I have lost my job and career, the breakdown of my marriage, and went through a period of homelessness."

Theme 11: Positive outlook

Despite the negative impacts of their neurological conditions on their quality of life, some respondents have expressed positive outlooks on their lives. They reported their improvements and adaptations and strive to live their lives fully.

"Mobility issues but I have adaptations."

"I pace my day to have quality of life. I am a qualified health professional who is more than capable of looking after herself. I also have qualifications in therapies so am self aware. Meditation is a way of life and has been for 20 years."

"I hope for steady, slow and continuing progress. I have become flexible around my condition and adjusted my expectations around quality of life. For example I do not know if I will work again in a paid job which would have been unthinkable by the previous 'me' but now I have conditions and caring responsibilities for a soon to be adult with special needs so these must take priority and I contribute this where I can."

"I struggle with certain daily tasks and I tire easily but I'm still determined to live my life fully."

Mental health

Current feelings

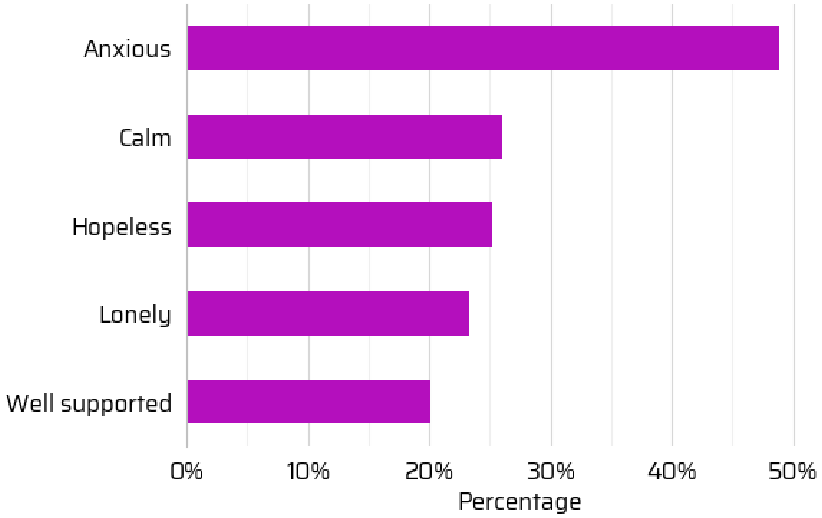


Figure 14: Feelings of the respondents at the time of the survey.

Table 11: Feelings of the respondents at the time of the survey.

Feelings	Respondents	Percentage
Anxious	335	48.91
Calm	178	25.99
Hopeless	173	25.26
Lonely	160	23.36
Well supported	138	20.15

Extent mental health needs are met.

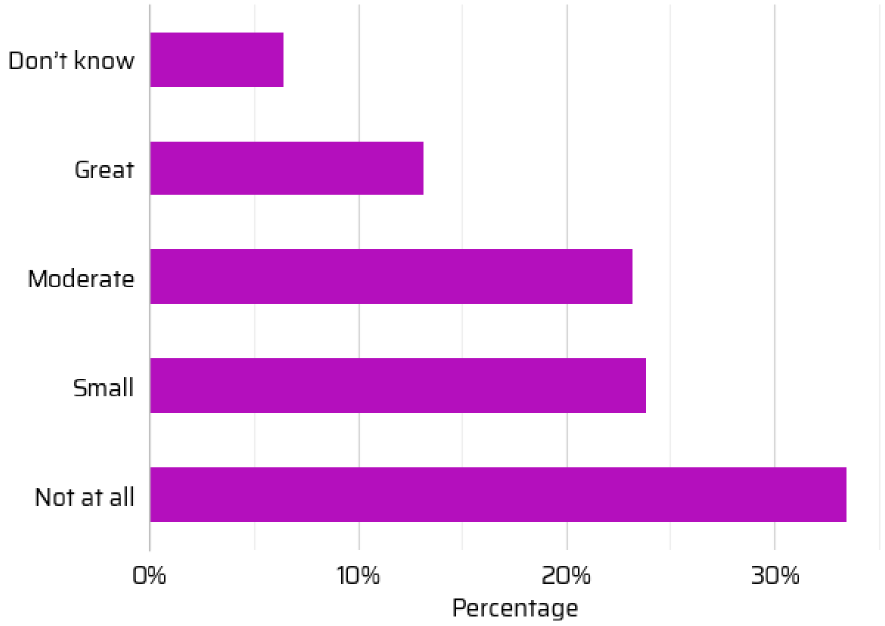


Figure 15 Extent respondents reported their mental health needs were being met.

Table 12 Extent respondents reported their mental health needs were being met.

Needs met	Respondents	Percentage
Don't know	44	6.42
Great	90	13.14
Moderate	159	23.21
Small	163	23.8
Not at all	229	33.43

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

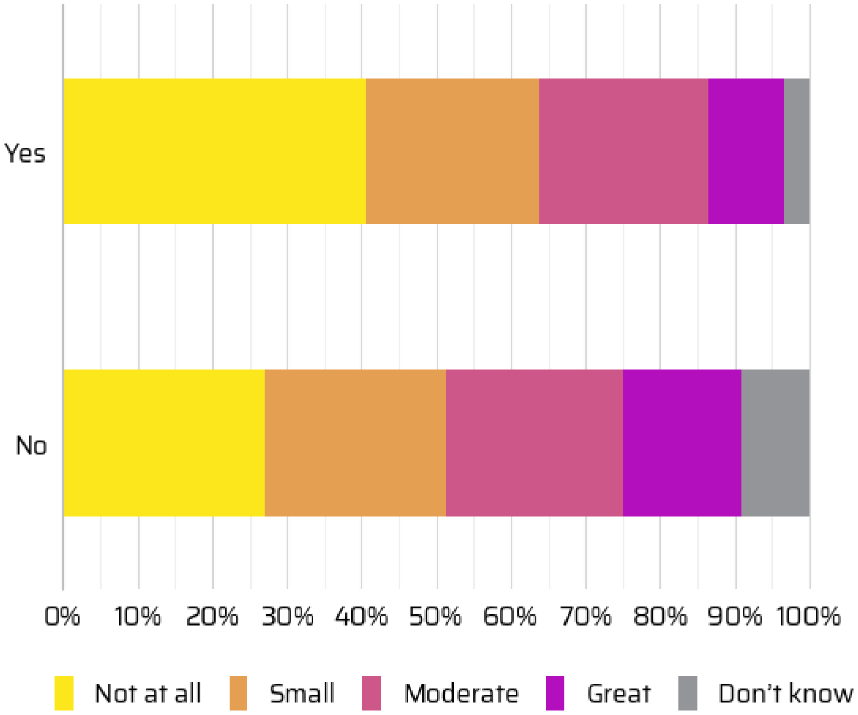


Figure 16 Extent respondents reported their mental health needs were being met, broken down by whether diagnosed with multiple neurological conditions.

Table 13 Extent respondents reported their mental health needs were being met, broken down by whether diagnosed with multiple neurological conditions.

Multiple neurological conditions	**Needs met**	**Respondents**	**Percentage**
Yes	Don't know	11	3.41
	Great	33	10.22
	Moderate	73	22.6
	Small	75	23.22
	Not at all	131	40.56
No	Don't know	33	9.12

	Great	57	15.75
	Moderate	86	23.76
	Small	88	24.31
	Not at all	98	27.07

Extent mental health needs are met by age group.

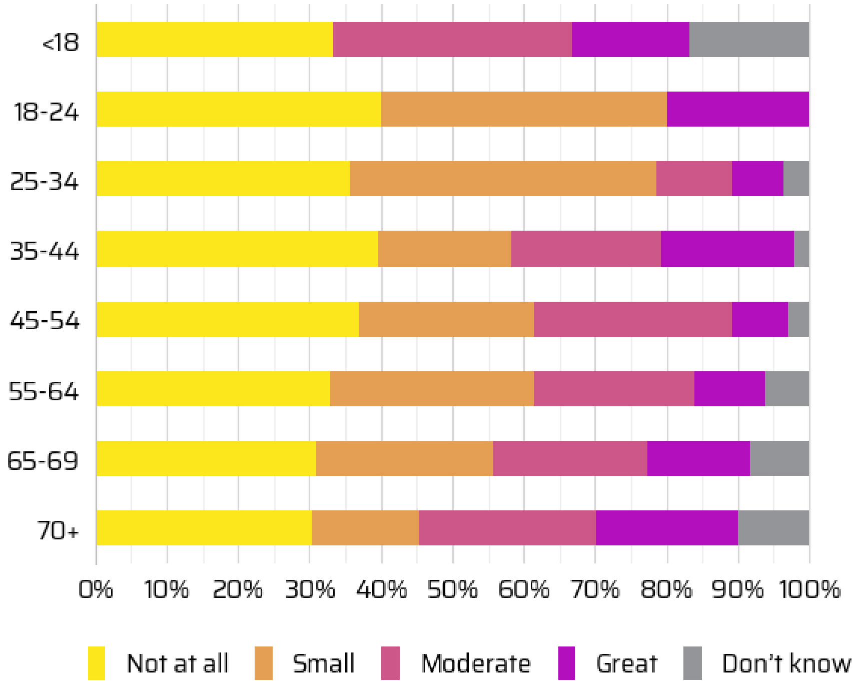


Figure 17 Extent respondents reported their mental health needs were being met, broken down by age group.

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

Age	Needs met	Respondents	Percentage
<18	Don't know	1	16.67
	Great	1	16.67
	Moderate	2	33.33
	Small	0	0.0

	Not at all	2	33.33
18-24	Don’t know	0	0.0
	Great	1	20.0
	Moderate	0	0.0
	Small	2	40.0
	Not at all	2	40.0
25-34	Don’t know	1	3.57
	Great	2	7.14
	Moderate	3	10.71
	Small	12	42.86
	Not at all	10	35.71
35-44	Don’t know	1	2.08
	Great	9	18.75
	Moderate	10	20.83
	Small	9	18.75
	Not at all	19	39.58
45-54	Don’t know	4	3.08
	Great	10	7.69
	Moderate	36	27.69
	Small	32	24.62
	Not at all	48	36.92
55-64	Don’t know	13	6.19
	Great	21	10.0
	Moderate	47	22.38
	Small	60	28.57
	Not at all	69	32.86
65-69	Don’t know	8	8.25

	Great	14	14.43
	Moderate	21	21.65
	Small	24	24.74
	Not at all	30	30.93
70+	Don’t know	16	9.94
	Great	32	19.88
	Moderate	40	24.84
	Small	24	14.91
	Not at all	49	30.43

Extent mental health needs are met by gender.

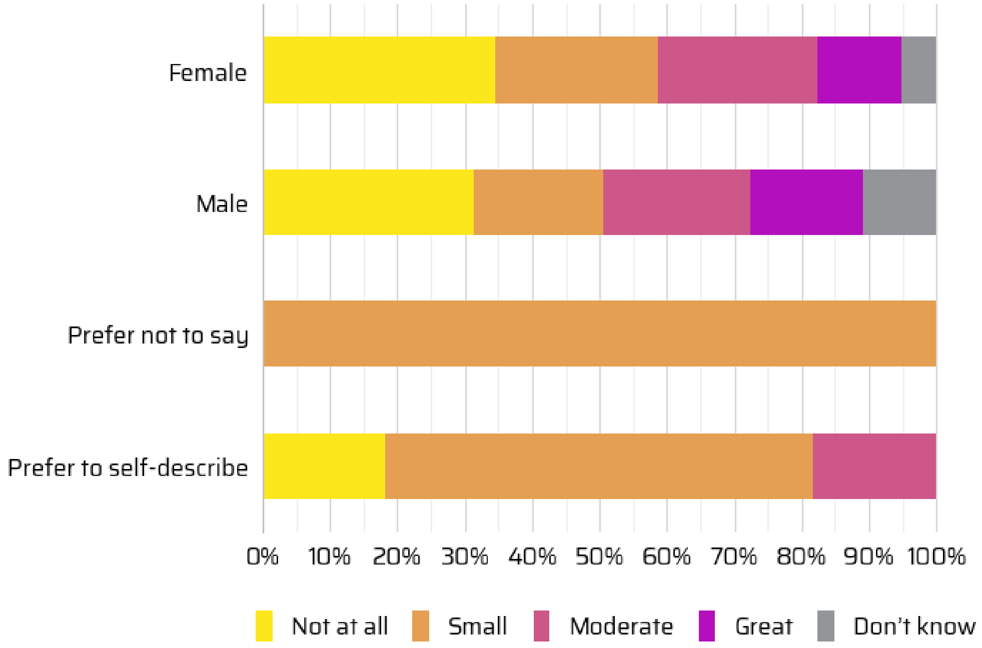
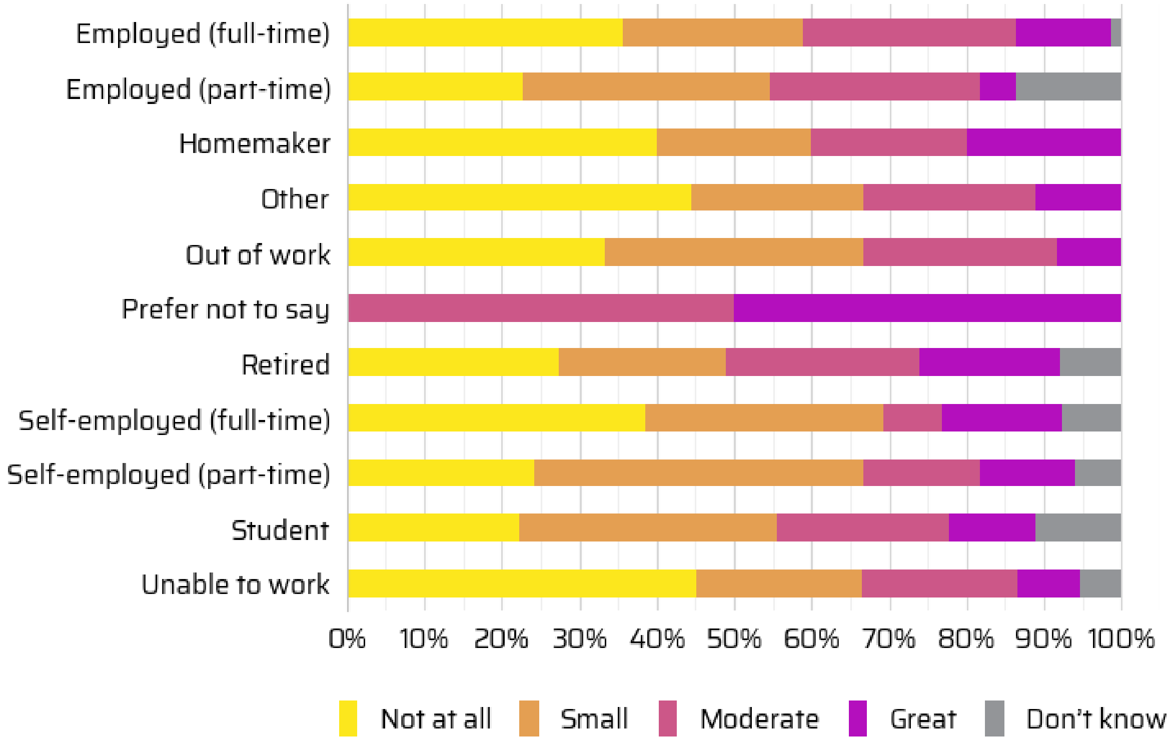


Figure 18 Extent respondents reported their mental health needs were being met, broken down by gender.

Table 15 Extent respondents reported their mental health needs were being met, broken down by gender.

Gender	**Needs met**	**Respondents**	**Percentage**

	Don’t know	27	5.22
	Great	64	12.38
Female	Moderate	123	23.79
	Small	125	24.18
	Not at all	178	34.43
	Don’t know	17	10.9
	Great	26	16.67
Male	Moderate	34	21.79
	Small	30	19.23
	Not at all	49	31.41
	Don’t know	0	0.0
	Great	0	0.0
Prefer not to say	Moderate	0	0.0
	Small	1	100.0
	Not at all	0	0.0
	Don’t know	0	0.0
	Great	0	0.0
Prefer to self-describe	Moderate	2	18.18
	Small	7	63.64
	Not at all	2	18.18



Extent mental health needs are met by employment status.

Figure 19 Extent respondents reported their mental health needs were being met, broken down by employment status.

Table 16 Extent respondents reported their mental health needs were being met, broken down by employment status.

Employment status	Needs met	Respondents	Percentage
Employed (full-time)	Don't know	1	1.37
	Great	9	12.33
	Moderate	20	27.4
	Small	17	23.29
	Not at all	26	35.62
Employed (part-time)	Don't know	6	13.64
	Great	2	4.55

	Moderate	12	27.27
	Small	14	31.82
	Not at all	10	22.73
Homemaker	Don’t know	0	0.0
	Great	1	20.0
	Moderate	1	20.0
	Small	1	20.0
	Not at all	2	40.0
Other	Don’t know	0	0.0
	Great	2	11.11
	Moderate	4	22.22
	Small	4	22.22
	Not at all	8	44.44
Out of work	Don’t know	0	0.0
	Great	1	8.33
	Moderate	3	25.0
	Small	4	33.33
	Not at all	4	33.33
Prefer not to say	Don’t know	0	0.0
	Great	1	50.0
	Moderate	1	50.0
	Small	0	0.0
	Not at all	0	0.0
Retired	Don’t know	23	7.99
	Great	52	18.06
	Moderate	72	25.0
	Small	62	21.53

	Not at all	79	27.43
Self-employed (full-time)	Don’t know	1	7.69
	Great	2	15.38
	Moderate	1	7.69
	Small	4	30.77
	Not at all	5	38.46
Self-employed (part-time)	Don’t know	2	6.06
	Great	4	12.12
	Moderate	5	15.15
	Small	14	42.42
	Not at all	8	24.24
Student	Don’t know	1	11.11
	Great	1	11.11
	Moderate	2	22.22
	Small	3	33.33
	Not at all	2	22.22
Unable to work	Don’t know	10	5.32
	Great	15	7.98
	Moderate	38	20.21
	Small	40	21.28
	Not at all	85	45.21

Extent mental health needs are met by number of dependents.

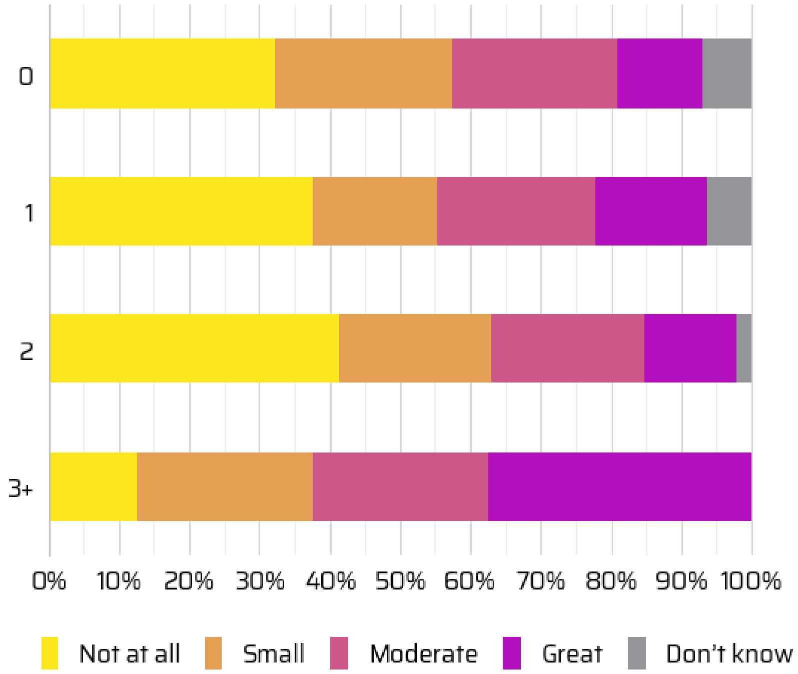


Figure 20 Extent respondents reported their mental health needs were being met, broken down by number of dependents.

Table 17 Extent respondents reported their mental health needs were being met, broken down by number of dependents.

Number of dependents	Needs met	Respondents	Percentage
0	Don't know	36	6.94
	Great	63	12.14
	Moderate	122	23.51
	Small	131	25.24
	Not at all	167	32.18
1	Don't know	7	6.25
	Great	18	16.07
	Moderate	25	22.32
	Small	20	17.86

	Not at all	42	37.5
2	Don’t know	1	2.17
	Great	6	13.04
	Moderate	10	21.74
	Small	10	21.74
	Not at all	19	41.3
3+	Don’t know	0	0.0
	Great	3	37.5
	Moderate	2	25.0
	Small	2	25.0
	Not at all	1	12.5

Overall Experience of health and care

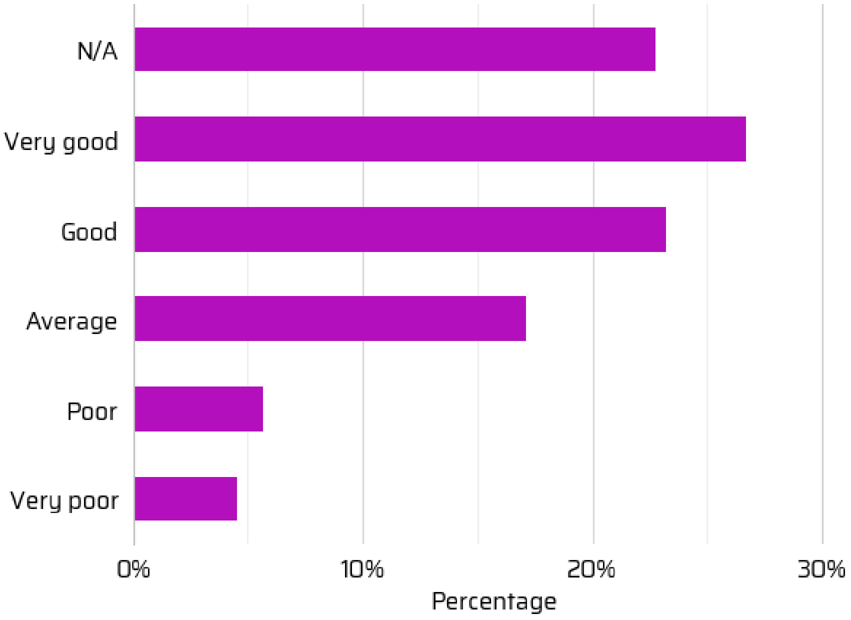


Figure 21 Overall experience of health and care.

Table 18 Overall experience of health and care.

Experience	Respondents	Percentage

N/A	156	22.77
Very good	183	26.72
Good	159	23.21
Average	117	17.08
Poor	39	5.69
Very poor	31	4.53

Overall experience of health and care by whether diagnosed with multiple neurological conditions.

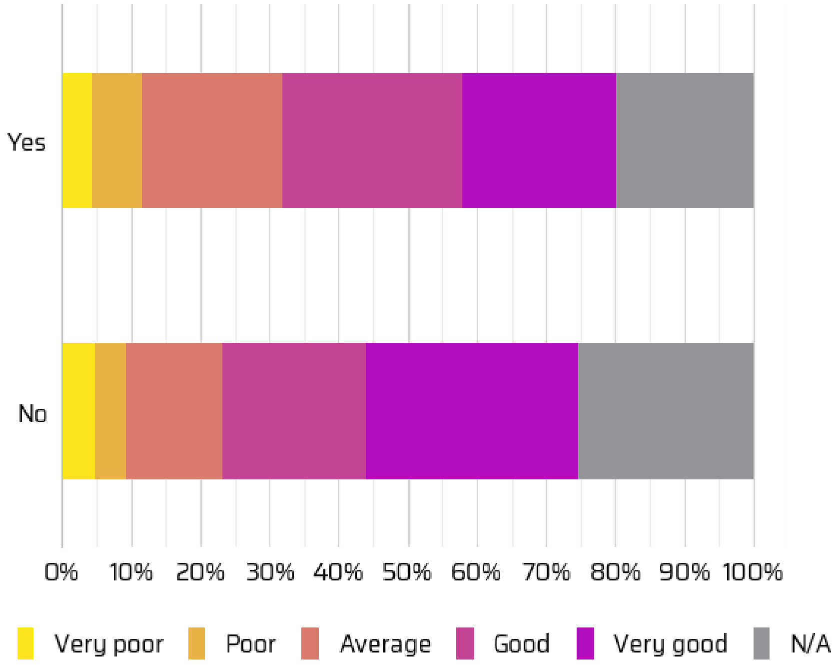


Figure 22 Overall experience of health and care, broken down by whether diagnosed with multiple neurological conditions.

Table 19 Overall experience of health and care, broken down by whether diagnosed with multiple neurological conditions.

Multiple neurological conditions	Experience	Respondents	Percentage
Yes	N/A	64	19.81

	Very good	72	22.29
	Good	84	26.01
	Average	66	20.43
	Poor	23	7.12
	Very poor	14	4.33
No	N/A	92	25.41
	Very good	111	30.66
	Good	75	20.72
	Average	51	14.09
	Poor	16	4.42
	Very poor	17	4.7

Overall experience of healthcare by age group.

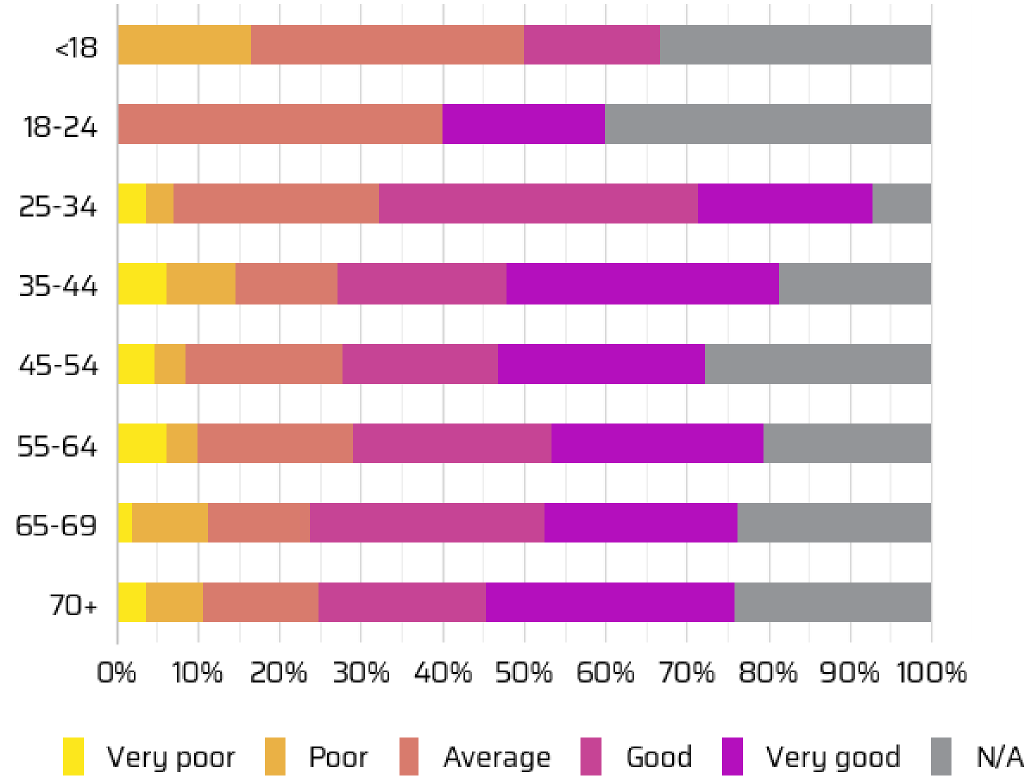


Figure 23 Overall experience of health and care, broken down by age group.

Table 20 Overall experience of health and care, broken down by age group.

Age	Experience	Respondents	Percentage
<18	N/A	2	33.33
	Very good	0	0.0
	Good	1	16.67
	Average	2	33.33
	Poor	1	16.67
	Very poor	0	0.0
18-24	N/A	2	40.0
	Very good	1	20.0
	Good	0	0.0
	Average	2	40.0
	Poor	0	0.0
	Very poor	0	0.0
25-34	N/A	2	7.14
	Very good	6	21.43
	Good	11	39.29
	Average	7	25.0
	Poor	1	3.57
	Very poor	1	3.57
35-44	N/A	9	18.75
	Very good	16	33.33
	Good	10	20.83
	Average	6	12.5
	Poor	4	8.33
	Very poor	3	6.25
45-54	N/A	36	27.69
	Very good	33	25.38

	Good	25	19.23
	Average	25	19.23
	Poor	5	3.85
	Very poor	6	4.62
55-64	N/A	43	20.48
	Very good	55	26.19
	Good	51	24.29
	Average	40	19.05
	Poor	8	3.81
	Very poor	13	6.19
65-69	N/A	23	23.71
	Very good	23	23.71
	Good	28	28.87
	Average	12	12.37
	Poor	9	9.28
	Very poor	2	2.06
70+	N/A	39	24.22
	Very good	49	30.43
	Good	33	20.5
	Average	23	14.29
	Poor	11	6.83
	Very poor	6	3.73

Overall experience of healthcare by gender.

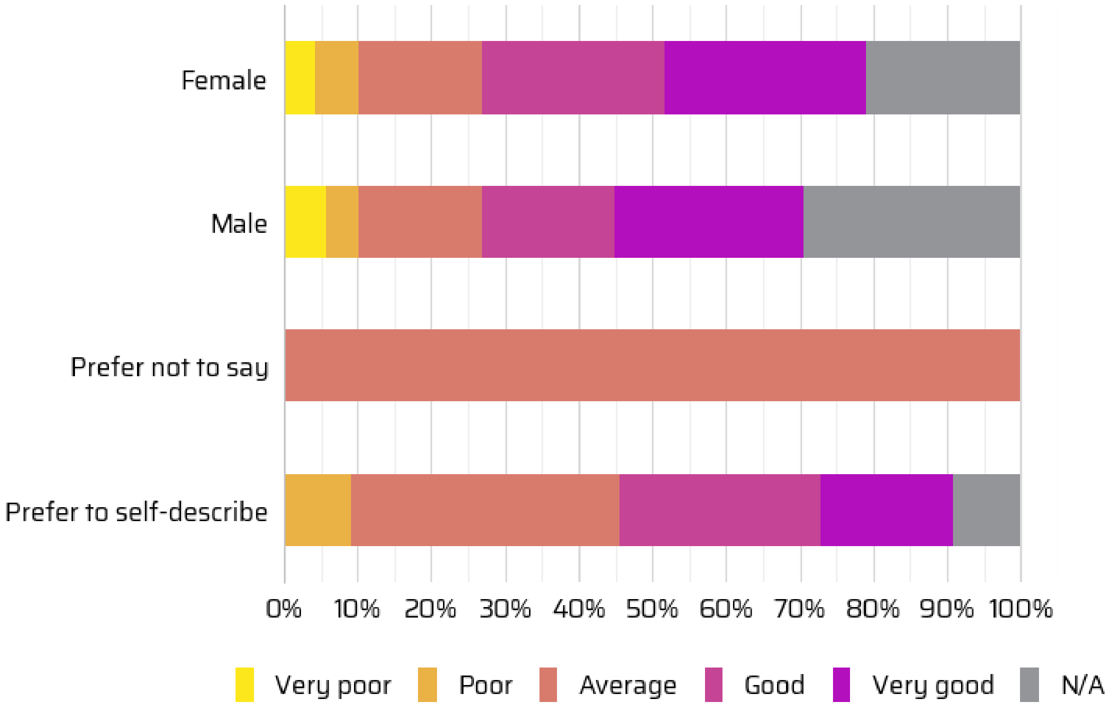


Figure 24 Overall experience of health and care, broken down by gender.

Table 21 Overall experience of health and care, broken down by gender.

Gender	Experience	Respondents	Percentage
Female	N/A	109	21.08
	Very good	141	27.27
	Good	128	24.76
	Average	86	16.63
	Poor	31	6.0
	Very poor	22	4.26
Male	N/A	46	29.49
	Very good	40	25.64
	Good	28	17.95
	Average	26	16.67

	Poor	7	4.49
	Very poor	9	5.77
Prefer not to say	N/A	0	0.0
	Very good	0	0.0
	Good	0	0.0
	Average	1	100.0
	Poor	0	0.0
	Very poor	0	0.0
Prefer to self-describe	N/A	1	9.09
	Very good	2	18.18
	Good	3	27.27
	Average	4	36.36
	Poor	1	9.09
	Very poor	0	0.0

Overall experience of health and care by employment status.

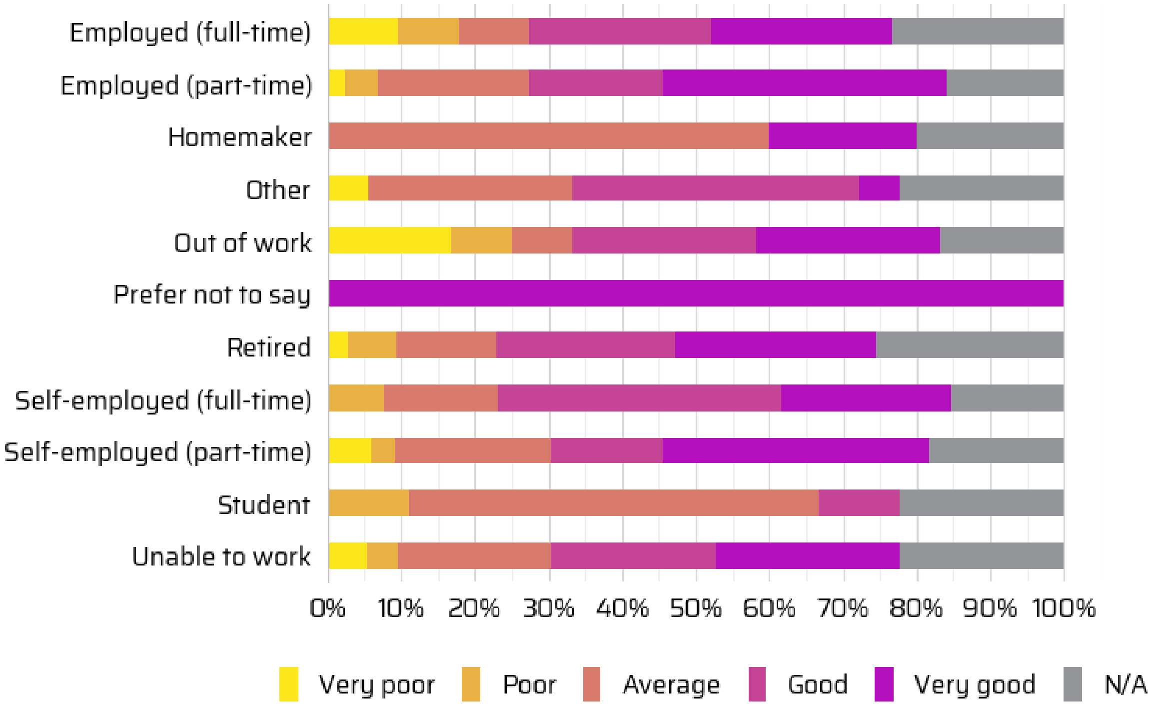


Figure 25 Overall experience of health and care, broken down by employment status.

Table 22 Overall experience of health and care, broken down by employment status.

Employment status	Experience	Respondents	Percentage
Employed (full-time)	N/A	17	23.29
	Very good	18	24.66
	Good	18	24.66
	Average	7	9.59
	Poor	6	8.22
	Very poor	7	9.59
Employed (part-time)	N/A	7	15.91
	Very good	17	38.64
	Good	8	18.18
	Average	9	20.45

	Poor	2	4.55
	Very poor	1	2.27
Homemaker	N/A	1	20.0
	Very good	1	20.0
	Good	0	0.0
	Average	3	60.0
	Poor	0	0.0
	Very poor	0	0.0
Other	N/A	4	22.22
	Very good	1	5.56
	Good	7	38.89
	Average	5	27.78
	Poor	0	0.0
	Very poor	1	5.56
Out of work	N/A	2	16.67
	Very good	3	25.0
	Good	3	25.0
	Average	1	8.33
	Poor	1	8.33
	Very poor	2	16.67
Prefer not to say	N/A	0	0.0
	Very good	2	100.0
	Good	0	0.0
	Average	0	0.0
	Poor	0	0.0
	Very poor	0	0.0
Retired	N/A	73	25.35

	Very good	79	27.43
	Good	70	24.31
	Average	39	13.54
	Poor	19	6.6
	Very poor	8	2.78
Self-employed (full-time)	N/A	2	15.38
	Very good	3	23.08
	Good	5	38.46
	Average	2	15.38
	Poor	1	7.69
	Very poor	0	0.0
Self-employed (part-time)	N/A	6	18.18
	Very good	12	36.36
	Good	5	15.15
	Average	7	21.21
	Poor	1	3.03
	Very poor	2	6.06
Student	N/A	2	22.22
	Very good	0	0.0
	Good	1	11.11
	Average	5	55.56
	Poor	1	11.11
	Very poor	0	0.0
Unable to work	N/A	42	22.34
	Very good	47	25.0
	Good	42	22.34
	Average	39	20.74

	Poor	8	4.26
	Very poor	10	5.32

Overall experience of health and care by number of dependents.

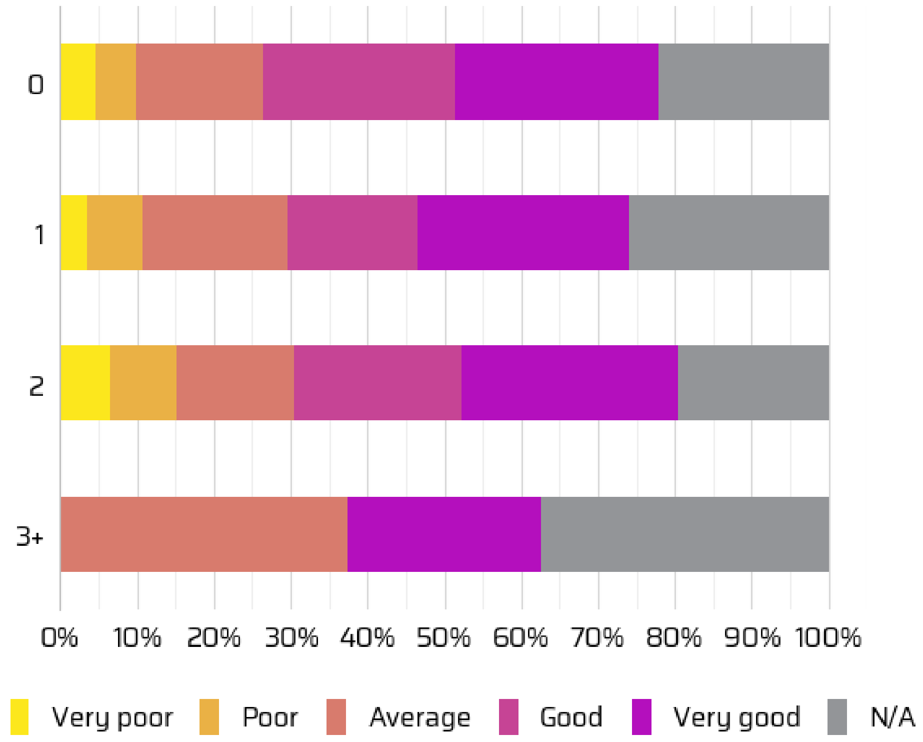


Figure 26 Overall experience of health and care, broken down by number of dependents.

Table 23 Overall experience of health and care, broken down by number of dependents.

Number of dependents	**Experience**	**Respondents**	**Percentage**
0	N/A	115	22.16
	Very good	137	26.4
	Good	130	25.05
	Average	86	16.57
	Poor	27	5.2
	Very poor	24	4.62

1	N/A	29	25.89
	Very good	31	27.68
	Good	19	16.96
	Average	21	18.75
	Poor	8	7.14
	Very poor	4	3.57
2	N/A	9	19.57
	Very good	13	28.26
	Good	10	21.74
	Average	7	15.22
	Poor	4	8.7
	Very poor	3	6.52
3+	N/A	3	37.5
	Very good	2	25.0
	Good	0	0.0
	Average	3	37.5
	Poor	0	0.0
	Very poor	0	0.0

Medical appointments

Access to medical appointments in the last eight weeks.

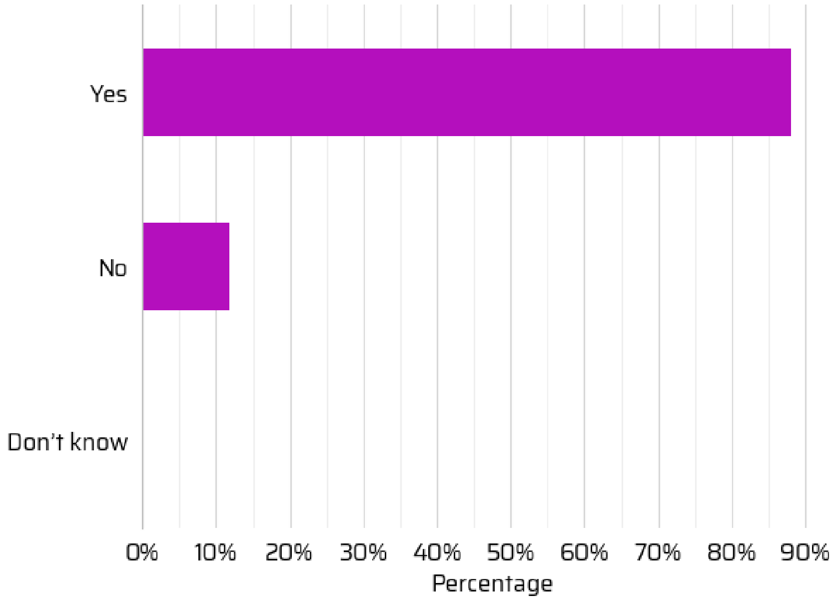


Figure 27 Access to medical appointments in the last eight weeks.

Table 24 Access to medical appointments in the last eight weeks.

Appointments	Respondents	Percentage
Yes	467	88.11
No	63	11.89
Don't know	0	0.0

Number of medical appointments.

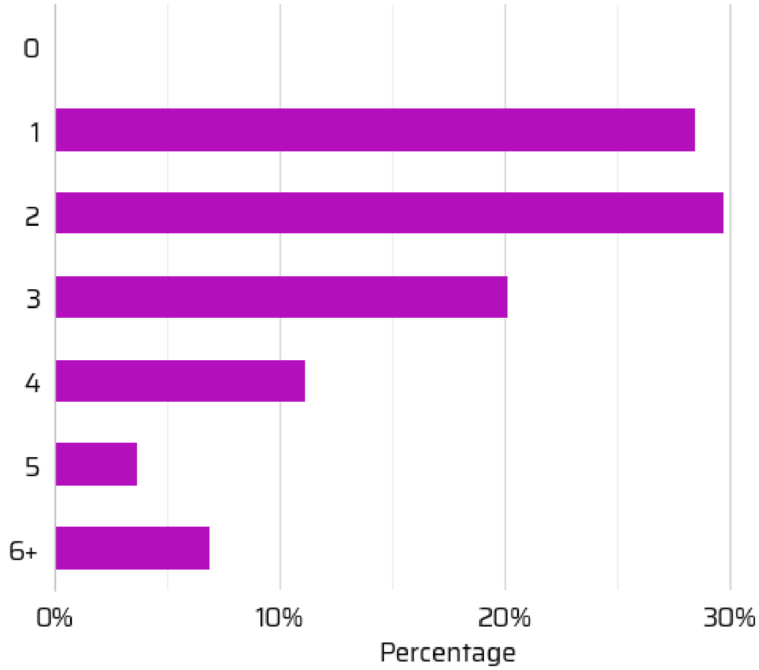


Figure 28 Number of medical appointments.

Table 25 Number of medical appointments.

Number of appointments	Respondents	Percentage
0	0	0.0
1	133	28.48
2	139	29.76
3	94	20.13
4	52	11.13
5	17	3.64
6+	32	6.85

Helpfulness of medical appointments.

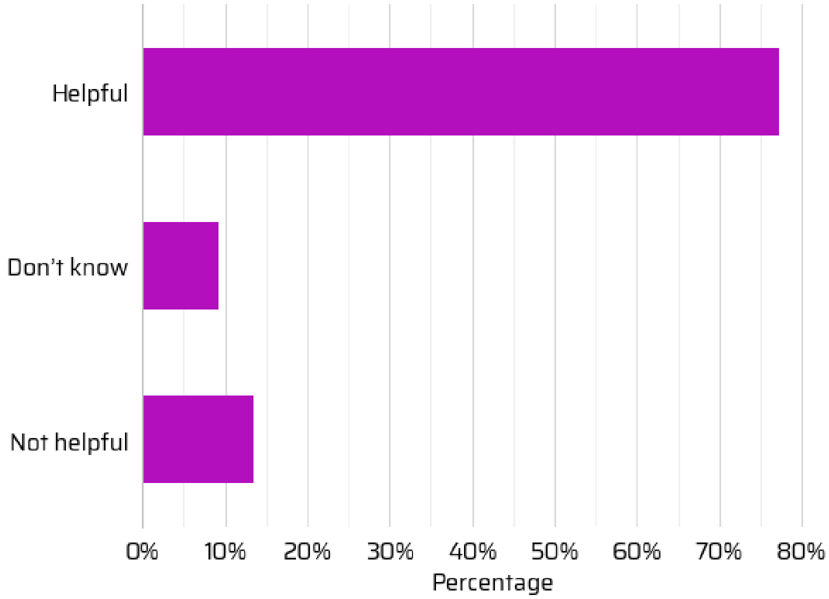


Figure 29 Helpfulness of medical appointments held in the last eight weeks.

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

Helpfulness	Respondents	Percentage
Helpful	964	77.31
Don’t know	115	9.22
Not helpful	168	13.47

Specialty of medical appointments.

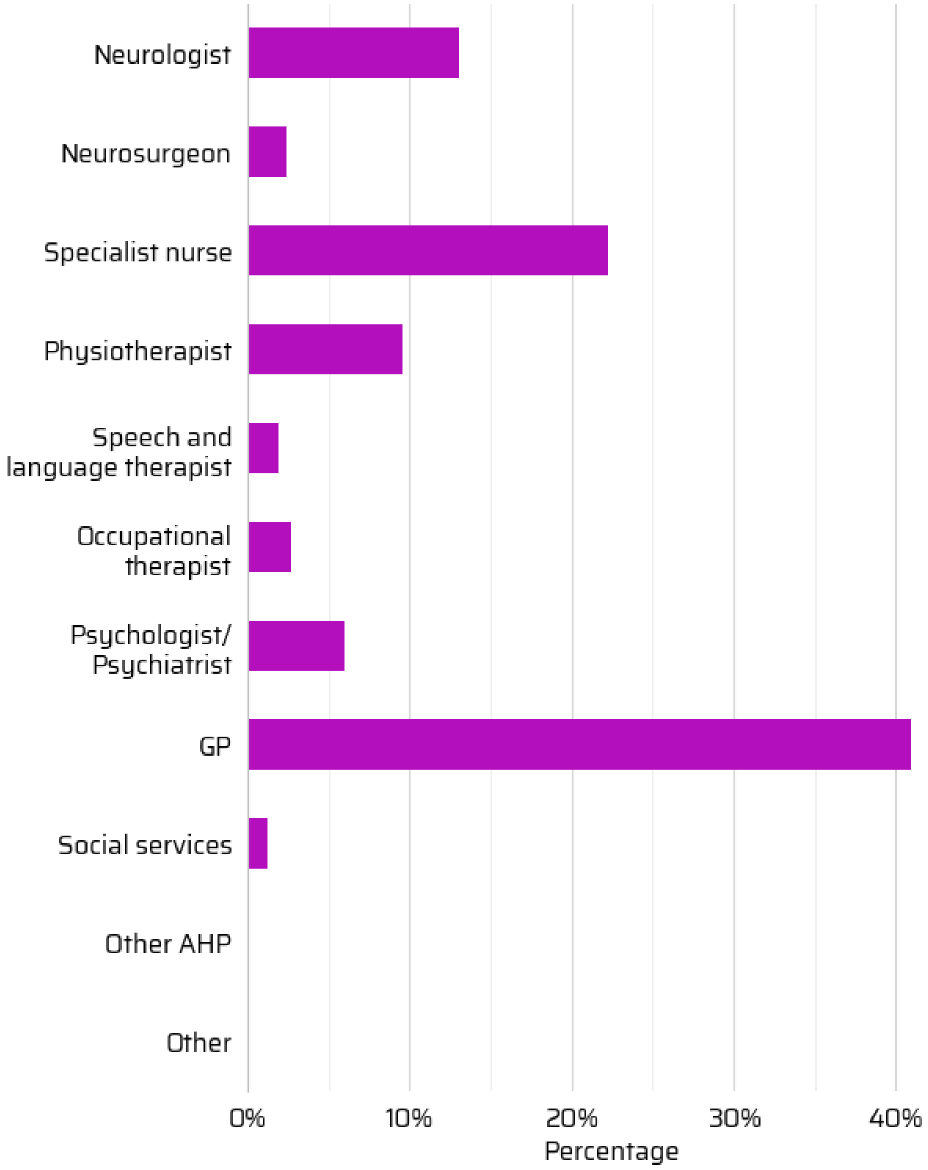


Figure 30 Speciality of the medical appointments held in the last eight weeks.

Table 27 Speciality of the medical appointments held in the last eight weeks.

Specialty	Respondents	Percentage
Neurologist	116	13.08
Neurosurgeon	21	2.37
Specialist nurse	197	22.21
Physiotherapist	85	9.58
Speech and language therapist	17	1.92
Occupational therapist	24	2.71
Psychologist/ Psychiatrist	53	5.98
GP	363	40.92
Social services	11	1.24
Other AHP	0	0.0
Other	0	0.0

Mode of medical appointments completed.

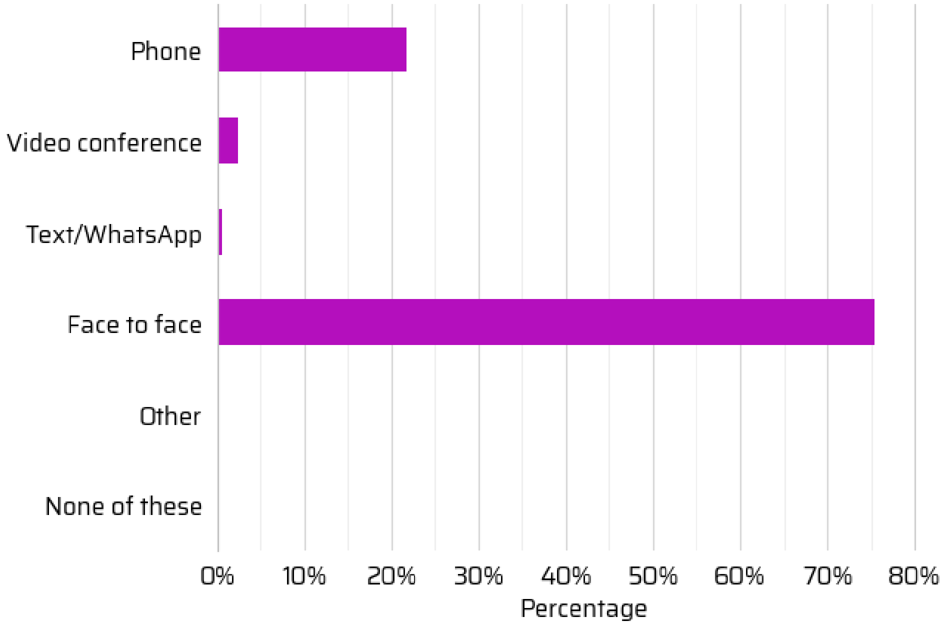


Figure 31 Mode of medical appointments completed in the last eight weeks.

Table 28 Mode of medical appointments completed in the last eight weeks.

Mode	Respondents	Percentage
Phone	261	21.68
Video conference	30	2.49
Text/WhatsApp	6	0.5
Face to face	907	75.33
Other	0	0.0
None of these	0	0.0

Frequency NHS A&E/emergency services were sought.

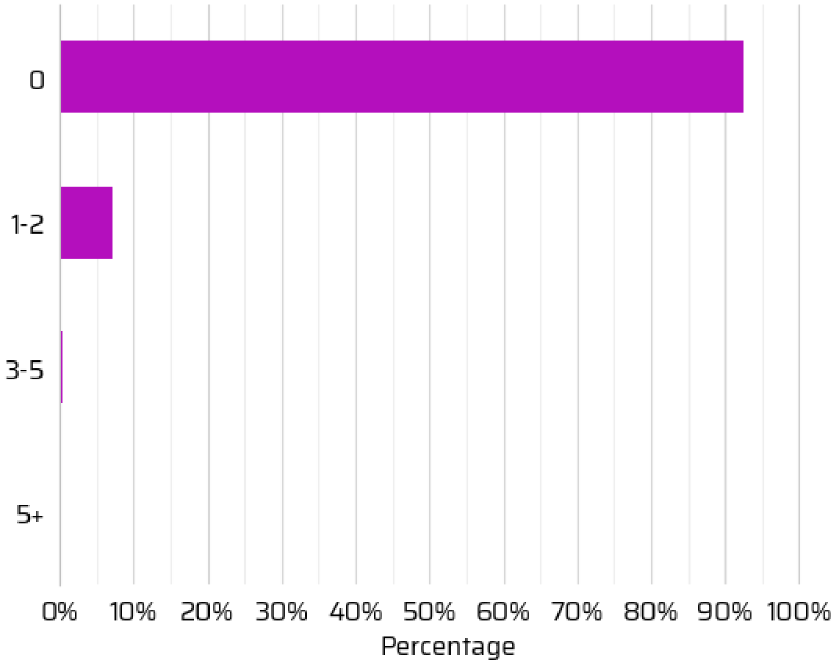


Figure 32 Frequency that NHS A&E/emergency services were sought in the last eight weeks.

Table 29 Frequency that NHS A&E/emergency services were sought in the last eight weeks.

Frequency	Respondents	Percentage
0	633	92.41
1-2	49	7.15
3-5	3	0.44
5+	0	0.0

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

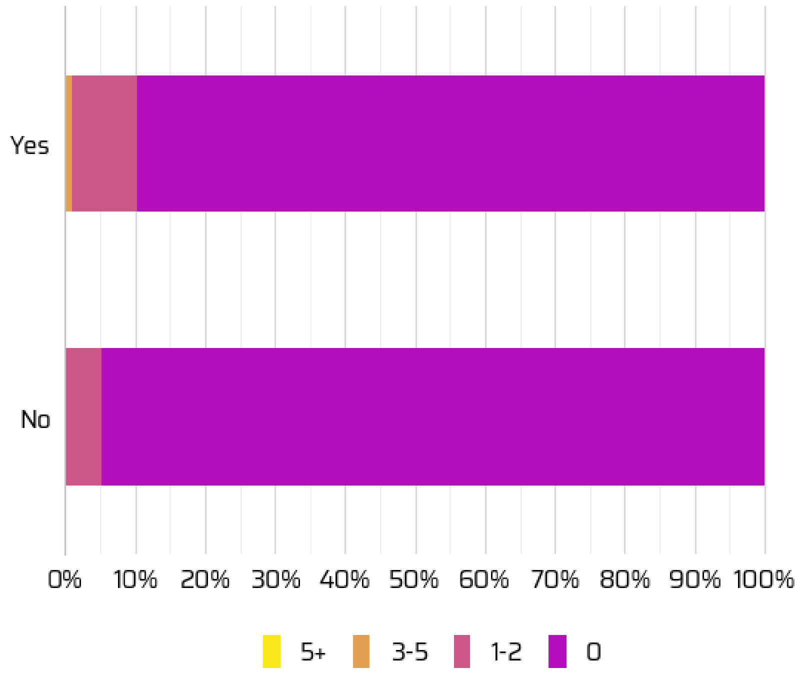


Figure 33 Frequency that NHS A&E/emergency services were sought, broken down by whether diagnosed with multiple neurological conditions.

Table 30 Frequency that NHS A&E/emergency services were sought, broken down by whether diagnosed with multiple neurological conditions.

Multiple neurological conditions	**Frequency**	**Respondents**	**Percentage**
Yes	0	290	89.78
	1-2	30	9.29
	3-5	3	0.93
	5+	0	0.0
No	0	343	94.75
	1-2	19	5.25
	3-5	0	0.0
	5+	0	0.0

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

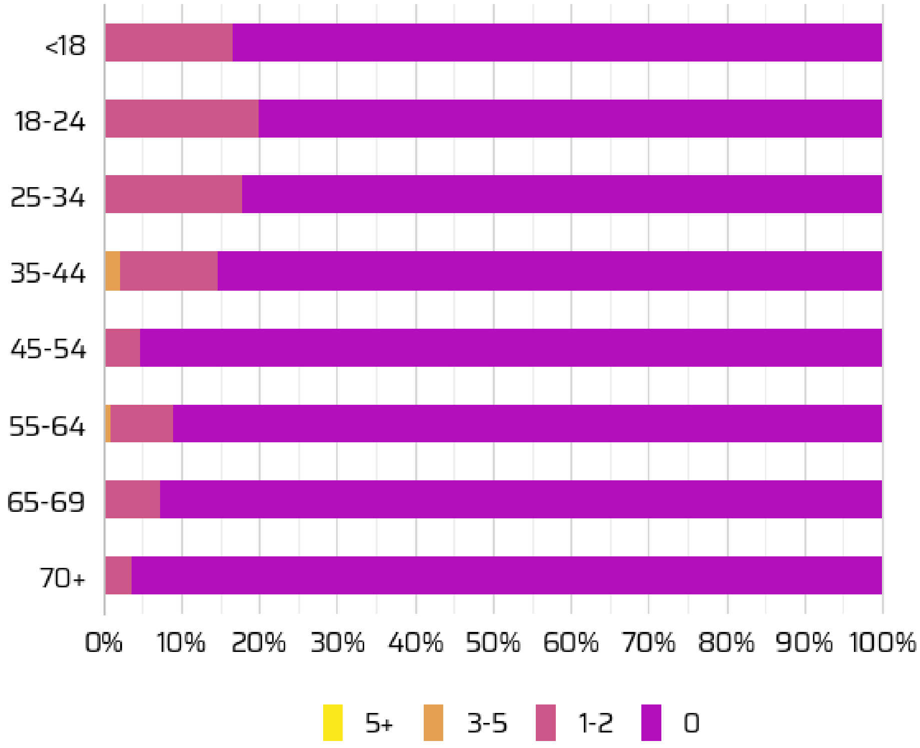


Figure 34 Frequency that NHS A&E/emergency services were sought, broken down by age group.

Table 31 Frequency that NHS A&E/emergency services were sought, broken down by age group.

Age	Frequency	Respondents	Percentage
<18	0	5	83.33
	1-2	1	16.67
	3-5	0	0.0
	5+	0	0.0
18-24	0	4	80.0
	1-2	1	20.0
	3-5	0	0.0
	5+	0	0.0
25-34	0	23	82.14
	1-2	5	17.86

	3-5	0	0.0
	5+	0	0.0
35-44	0	41	85.42
	1-2	6	12.5
	3-5	1	2.08
	5+	0	0.0
45-54	0	124	95.38
	1-2	6	4.62
	3-5	0	0.0
	5+	0	0.0
55-64	0	191	90.95
	1-2	17	8.1
	3-5	2	0.95
	5+	0	0.0
65-69	0	90	92.78
	1-2	7	7.22
	3-5	0	0.0
	5+	0	0.0
70+	0	155	96.27
	1-2	6	3.73
	3-5	0	0.0
	5+	0	0.0

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

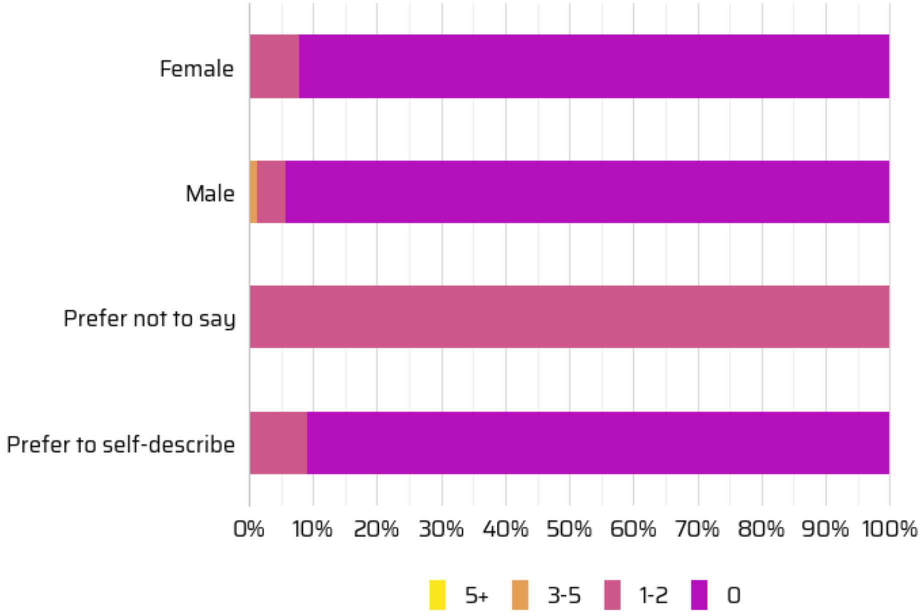


Figure 35 Frequency that NHS A&E/emergency services were sought, broken down by gender.

Table 32 Frequency that NHS A&E/emergency services were sought, broken down by gender.

Gender	Frequency	Respondents	Percentage
Female	0	476	92.07
	1-2	40	7.74
	3-5	1	0.19
	5+	0	0.0
Male	0	147	94.23
	1-2	7	4.49
	3-5	2	1.28
	5+	0	0.0
Prefer not to say	0	0	0.0
	1-2	1	100.0
	3-5	0	0.0
	5+	0	0.0

Prefer to self-describe	0	10	90.91
	1-2	1	9.09
	3-5	0	0.0
	5+	0	0.0

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

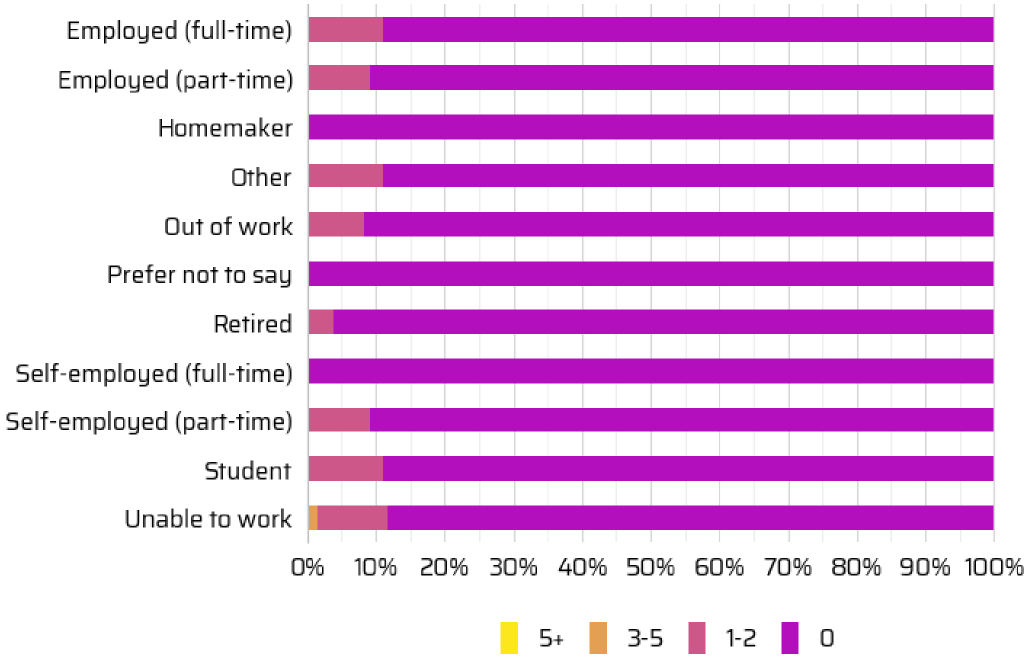


Figure 36 Frequency that NHS A&E/emergency services were sought, broken down by employment status.

Table 33 Frequency that NHS A&E/emergency services were sought, broken down by employment status.

Employment status	Frequency	Respondents	Percentage
Employed (full-time)	0	65	89.04
	1-2	8	10.96
	3-5	0	0.0
	5+	0	0.0

Employed (part-time)	0	40	90.91
	1-2	4	9.09
	3-5	0	0.0
	5+	0	0.0
Homemaker	0	5	100.0
	1-2	0	0.0
	3-5	0	0.0
	5+	0	0.0
Other	0	16	88.89
	1-2	2	11.11
	3-5	0	0.0
	5+	0	0.0
Out of work	0	11	91.67
	1-2	1	8.33
	3-5	0	0.0
	5+	0	0.0
Prefer not to say	0	2	100.0
	1-2	0	0.0
	3-5	0	0.0
	5+	0	0.0
Retired	0	277	96.18
	1-2	11	3.82
	3-5	0	0.0
	5+	0	0.0
Self-employed (full-time)	0	13	100.0
	1-2	0	0.0
	3-5	0	0.0

	5+	0	0.0
Self-employed (part-time)	0	30	90.91
	1-2	3	9.09
	3-5	0	0.0
	5+	0	0.0
Student	0	8	88.89
	1-2	1	11.11
	3-5	0	0.0
	5+	0	0.0
Unable to work	0	166	88.3
	1-2	19	10.11
	3-5	3	1.6
	5+	0	0.0

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

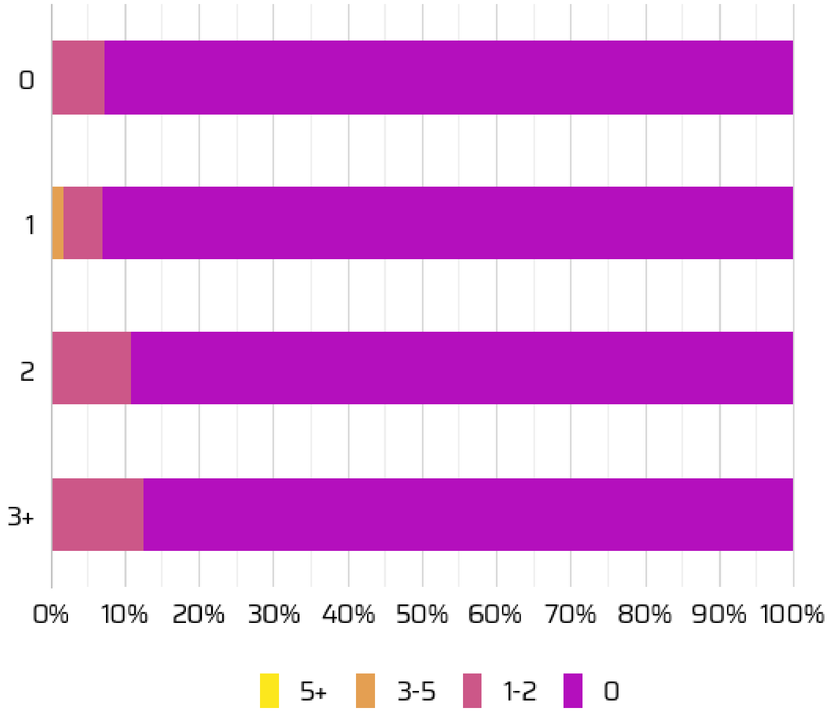


Figure 37 Frequency that NHS A&E/emergency services were sought, broken down by number of dependents.

Table 34 Frequency that NHS A&E/emergency services were sought, broken down by number of dependents.

Number of dependents	Frequency	Respondents	Percentage
0	0	481	92.68
	1-2	37	7.13
	3-5	1	0.19
	5+	0	0.0
1	0	104	92.86
	1-2	6	5.36
	3-5	2	1.79

	5+	0	0.0
2	0	41	89.13
	1-2	5	10.87
	3-5	0	0.0
	5+	0	0.0
3+	0	7	87.5
	1-2	1	12.5
	3-5	0	0.0
	5+	0	0.0

Demographics

Sample size

Total number of respondents: 685

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 323 respondents, equating to 47.15% of the respondents that had answered this question, indicated that they have multiple (i.e., more than one) neurological conditions.

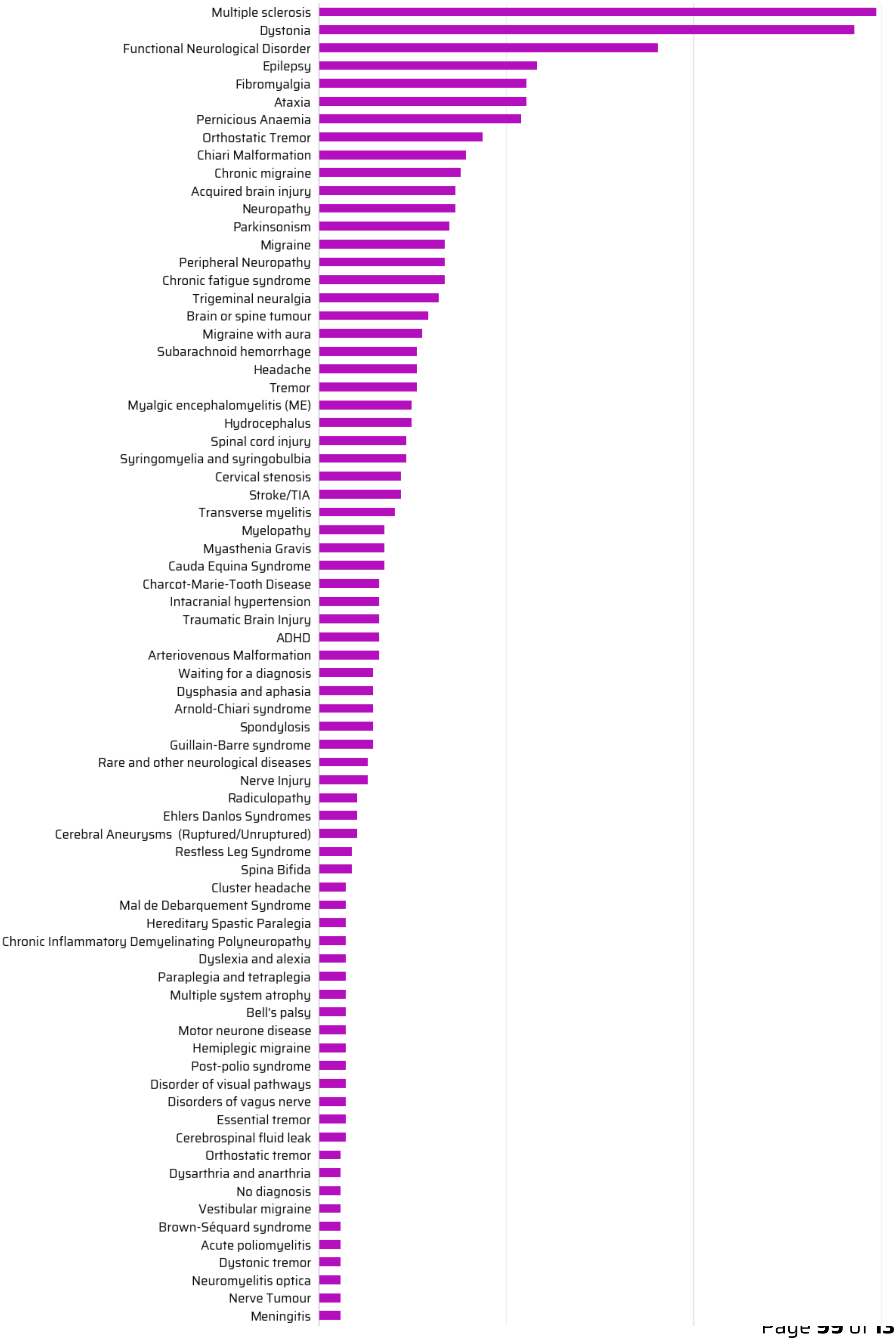

Multiple sclerosis
Dystonia
Functional Neurological Disorder
Epilepsy
Fibromyalgia
Ataxia
Pernicious Anaemia
Orthostatic Tremor
Chiari Malformation
Chronic migraine
Acquired brain injury
Neuropathy
Parkinsonism
Migraine
Peripheral Neuropathy
Chronic fatigue syndrome
Trigeminal neuralgia
Brain or spine tumour
Migraine with aura
Subarachnoid hemorrhage
Headache
Tremor
Myalgic encephalomyelitis (ME)
Hydrocephalus
Spinal cord injury
Syringomyelia and syringobulbia
Cervical stenosis
Stroke/TIA
Transverse myelitis
Myelopathy
Myasthenia Gravis
Cauda Equina Syndrome
Charcot-Marie-Tooth Disease
Intacranial hypertension
Traumatic Brain Injury
ADHD
Arteriovenous Malformation
Waiting for a diagnosis
Dysphasia and aphasia
Arnold-Chiari syndrome
Spondylosis
Guillain-Barre syndrome
Rare and other neurological diseases
Nerve Injury
Radiculopathy
Ehlers Danlos Syndromes
Cerebral Aneurysms (Ruptured/Unruptured)
Restless Leg Syndrome
Spina Bifida
Cluster headache
Mal de Debarquement Syndrome
Hereditary Spastic Paralegia
Chronic Inflammatory Demyelinating Polyneuropathy
Dyslexia and alexia
Paraplegia and tetraplegia
Multiple system atrophy
Bell's palsy
Motor neurone disease
Hemiplegic migraine
Post-polio syndrome
Disorder of visual pathways
Disorders of vagus nerve
Essential tremor
Cerebrospinal fluid leak
Orthostatic tremor
Dysarthria and anarthria
No diagnosis
Vestibular migraine
Brown-Séquard syndrome
Acute poliomyelitis
Dystonic tremor
Neuromyelitis optica
Nerve Tumour
Meningitis

Figure 38 Neurological conditions respondents had been diagnosed with.

Table 35 Neurological conditions respondents had been diagnosed with.

Condition	Respondents	Percentage
Multiple sclerosis	102	14.89
Dystonia	98	14.31
Functional Neurological Disorder	62	9.05
Epilepsy	40	5.84
Fibromyalgia	38	5.55
Ataxia	38	5.55
Pernicious Anaemia	37	5.4
Orthostatic Tremor	30	4.38
Chiari Malformation	27	3.94

Chronic migraine	26	3.8
Neuropathy	25	3.65
Acquired brain injury	25	3.65
Parkinsonism	24	3.5
Migraine	23	3.36
Peripheral Neuropathy	23	3.36
Chronic fatigue syndrome	23	3.36
Trigeminal neuralgia	22	3.21
Brain or spine tumour	20	2.92
Migraine with aura	19	2.77
Subarachnoid hemorrhage	18	2.63
Headache	18	2.63
Tremor	18	2.63
Myalgic encephalomyelitis (ME)	17	2.48
Hydrocephalus	17	2.48
Spinal cord injury	16	2.34
Syringomyelia and syringobulbia	16	2.34
Cervical stenosis	15	2.19
Stroke/TIA	15	2.19
Transverse myelitis	14	2.04
Myelopathy	12	1.75
Myasthenia Gravis	12	1.75
Cauda Equina Syndrome	12	1.75
Charcot-Marie-Tooth Disease	11	1.61
Intacranial hypertension	11	1.61
Traumatic Brain Injury	11	1.61
ADHD	11	1.61

Arteriovenous Malformation	11	1.61
Guillain-Barre syndrome	10	1.46
Spondylosis	10	1.46
Arnold-Chiari syndrome	10	1.46
Dysphasia and aphasia	10	1.46
Waiting for a diagnosis	10	1.46
Rare and other neurological diseases	9	1.31
Nerve Injury	9	1.31
Radiculopathy	7	1.02
Ehlers Danlos Syndromes	7	1.02
Cerebral Aneurysms (Ruptured/Unruptured)	7	1.02
Restless Leg Syndrome	6	0.88
Spina Bifida	6	0.88
Paraplegia and tetraplegia	5	0.73
Dyslexia and alexia	5	0.73
Cluster headache	5	0.73
Hereditary Spastic Paralegia	5	0.73
Mal de Debarquement Syndrome	5	0.73
Multiple system atrophy	5	0.73
Chronic Inflammatory Demyelinating Polyneuropathy	5	0.73
Bell's palsy	5	0.73
Cerebrospinal fluid leak	5	0.73
Motor neurone disease	5	0.73
Hemiplegic migraine	5	0.73
Post-polio syndrome	5	0.73
Disorder of visual pathways	5	0.73
Disorders of vagus nerve	5	0.73

Essential tremor	5	0.73
Dementia	4	0.58
Meningitis	4	0.58
Dystonic tremor	4	0.58
Nerve Tumour	4	0.58
Orthostatic tremor	4	0.58
Neuromyelitis optica	4	0.58
Dysarthria and anarthria	4	0.58
Acute poliomyelitis	4	0.58
Brown-Séquard syndrome	4	0.58
Vestibular migraine	4	0.58
No diagnosis	4	0.58
Complex regional pain syndrome	4	0.58
Bipolar	3	0.44
Clonic hemifacial spasm	3	0.44
Dysexecutive Syndrome	3	0.44
Schwanomatosis	3	0.44
Tarlov Cysts	3	0.44
Migraine without aura	3	0.44
Long COVID	3	0.44
Parkinsonian tremor	3	0.44
Superficial Siderosis	3	0.44
Cavernoma	3	0.44
Short Fibre Neuropathy	2	0.29
Disorders of multiple cranial nerves	2	0.29
Chagas' disease	2	0.29
Neurofibromatosis	2	0.29

Optic atrophy	2	0.29
Hemiplegia	2	0.29
Disorders of other visual pathways	2	0.29
Demyelinating disease	2	0.29
Headache associated with exercise	2	0.29
Papilloedema	2	0.29
Myositis	2	0.29
Abdominal migraine	2	0.29
Tethered Cord	2	0.29
Meningeal tuberculoma	1	0.15
Eaton-Lambert syndrome	1	0.15
Menstrual migraine	1	0.15
Cerebral cysts	1	0.15
Encephalitis	1	0.15
Extradural and subdural abscess	1	0.15
Neurosarcoidosis	1	0.15
Tourette Syndrome	1	0.15
Nerve palsy	1	0.15
Muscular dystrophy	1	0.15
Disorders of other specified cranial nerves	1	0.15
Tension type headache	1	0.15
Migraine with brainstem aura	1	0.15
Vascular myelopathies	1	0.15
Huntington's disease	1	0.15

Recency of diagnosis.

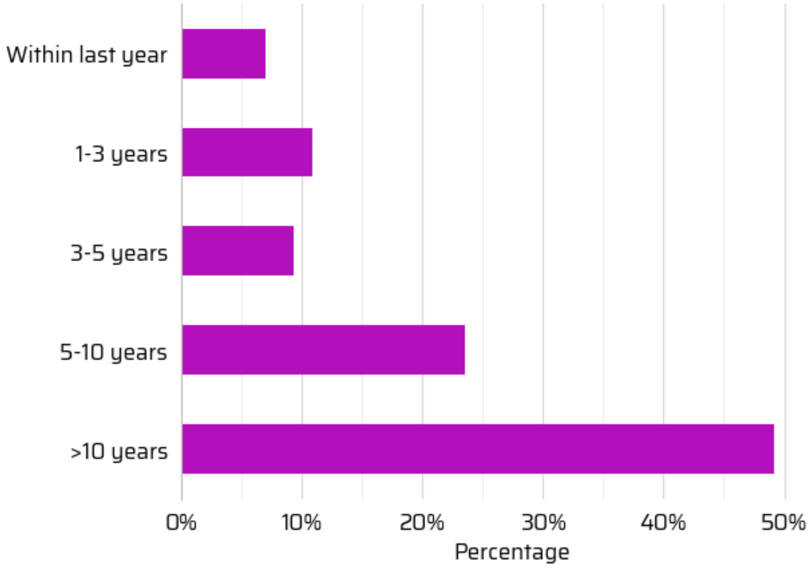


Figure 39 Recency of the respondents' first neurological condition diagnosis.

Table 36 Recency of the respondents' first neurological condition diagnosis.

Recency	Respondents	Percentage
Within last year	48	7.01
1-3 years	75	10.95
3-5 years	64	9.34
5-10 years	161	23.5
>10 years	337	49.2

Multiple neurological conditions

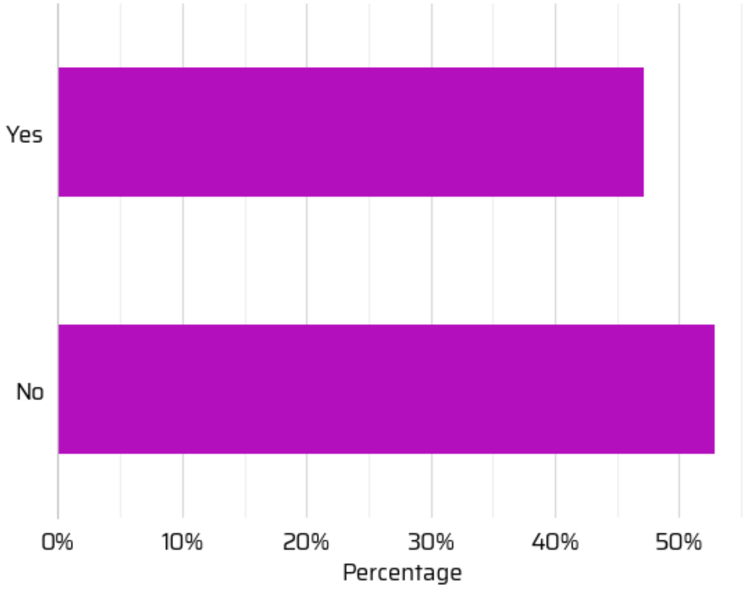


Figure 40 Whether respondents were diagnosed with multiple neurological conditions.

Table 37 Whether respondents were diagnosed with multiple neurological conditions.

Multiple neurological conditions	Respondents	Percentage
Yes	323	47.15
No	362	52.85

Number of non-neurological co-occurring conditions

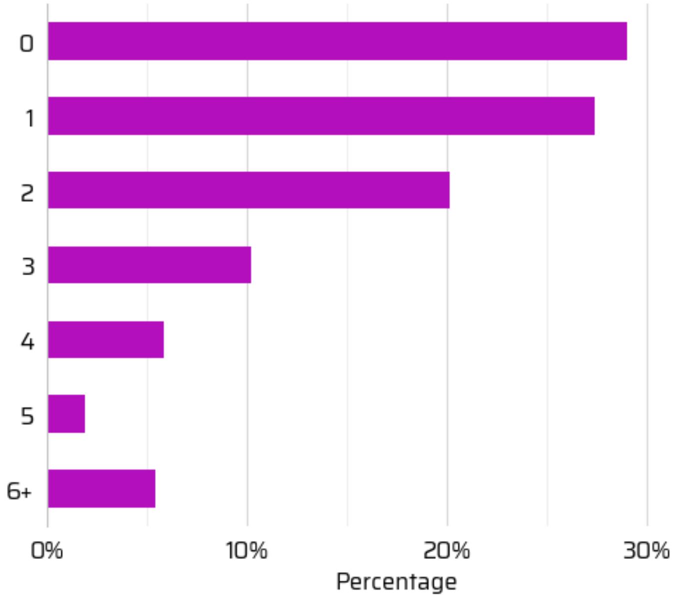


Figure 41 Number of non-neurological conditions that respondents were diagnosed with that co-occur with their neurological condition(s).

Table 38 Number of non-neurological conditions that respondents were diagnosed with that co-occur with their neurological condition(s).

Number of conditions	Respondents	Percentage
0	199	29.05
1	188	27.45
2	138	20.15
3	70	10.22
4	40	5.84
5	13	1.9
6+	37	5.4

Gender

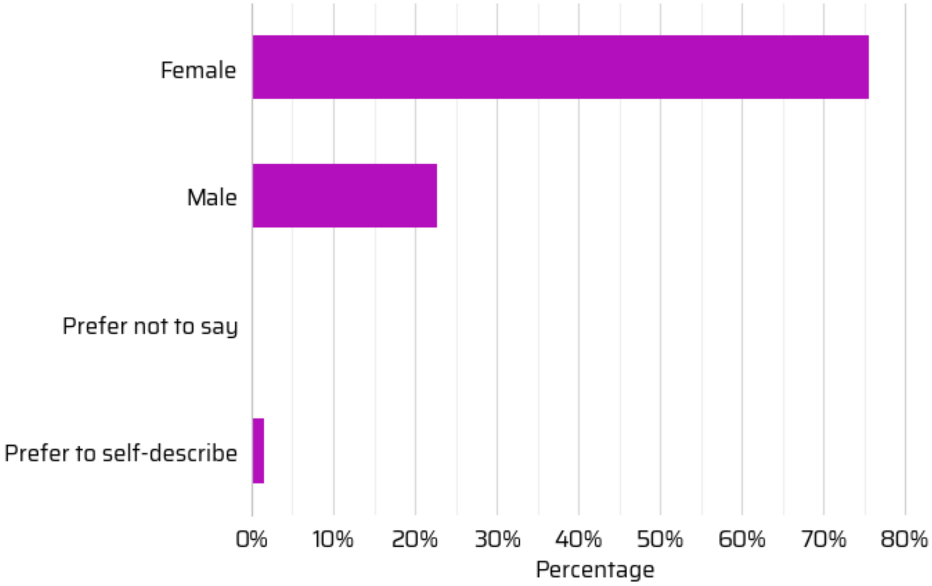


Figure 42 Gender of respondents.

Table 39 Gender of respondents.

Gender	Respondents	Percentage
Female	517	75.47
Male	156	22.77
Prefer not to say	1	0.15
Prefer to self-describe	11	1.61

Sexual orientation.

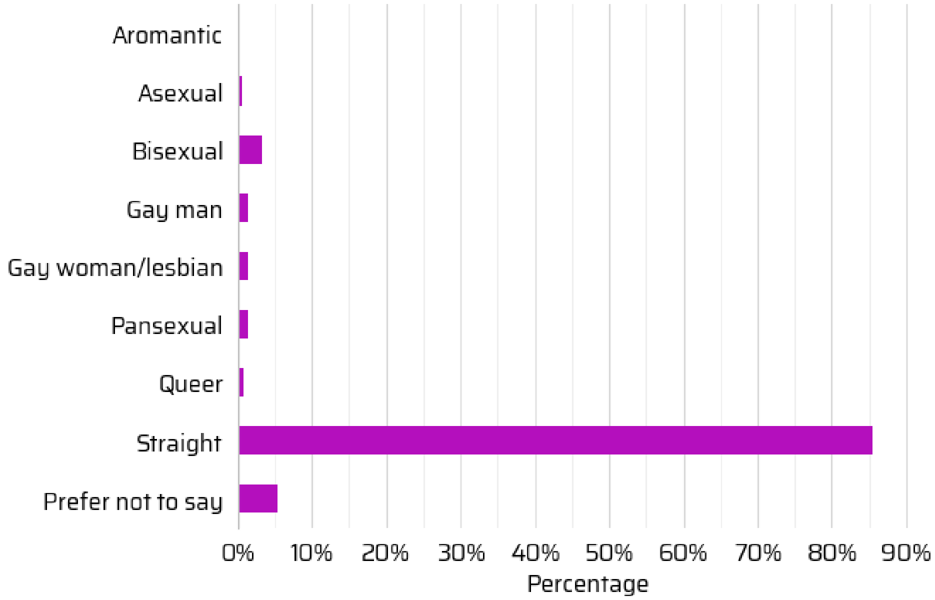


Figure 43 Sexual orientation of respondents.

Table 40 Sexual orientation of respondents.

Sexual orientation	Respondents	Percentage
Aromantic	0	0.0
Asexual	4	0.59
Bisexual	23	3.4
Gay man	10	1.48
Gay woman/lesbian	10	1.48
Pansexual	9	1.33
Queer	6	0.89
Straight	577	85.36
Prefer not to say	37	5.47

Age

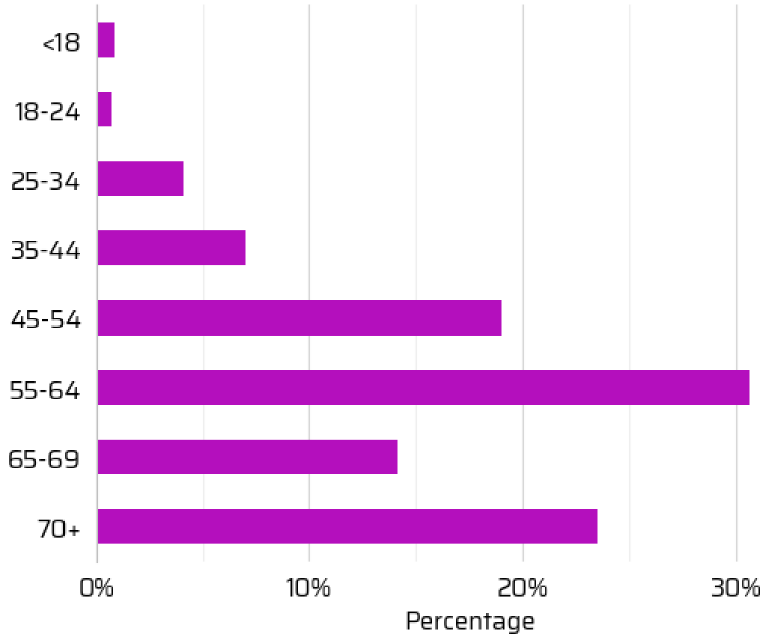


Figure 44 Age of respondents.

Table 41 Age of respondents.

Age	Respondents	Percentage
<18	6	0.88
18-24	5	0.73
25-34	28	4.09
35-44	48	7.01
45-54	130	18.98
55-64	210	30.66
65-69	97	14.16
70+	161	23.5

Ethnic group

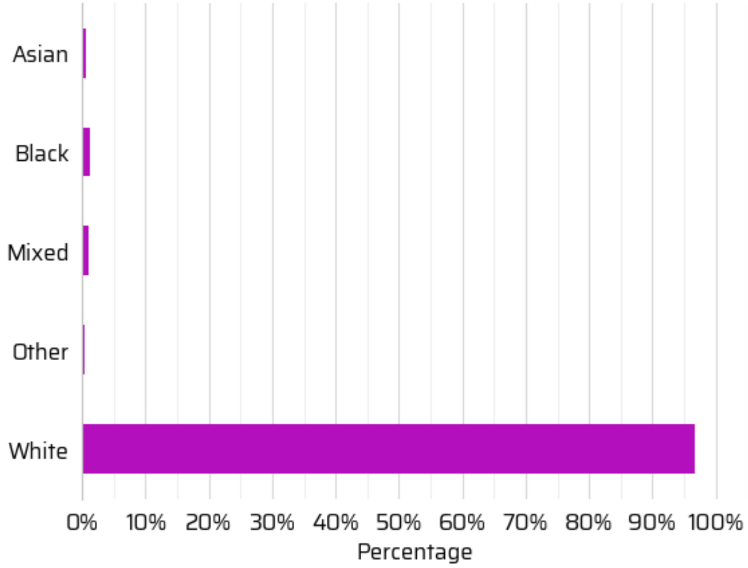


Figure 45 Ethnic group of respondents.

Table 42 Ethnic group of respondents.

Ethnic group	Respondents	Percentage
Asian	4	0.58
Black	8	1.17
Mixed	7	1.02
Other	3	0.44
White	663	96.79

Location

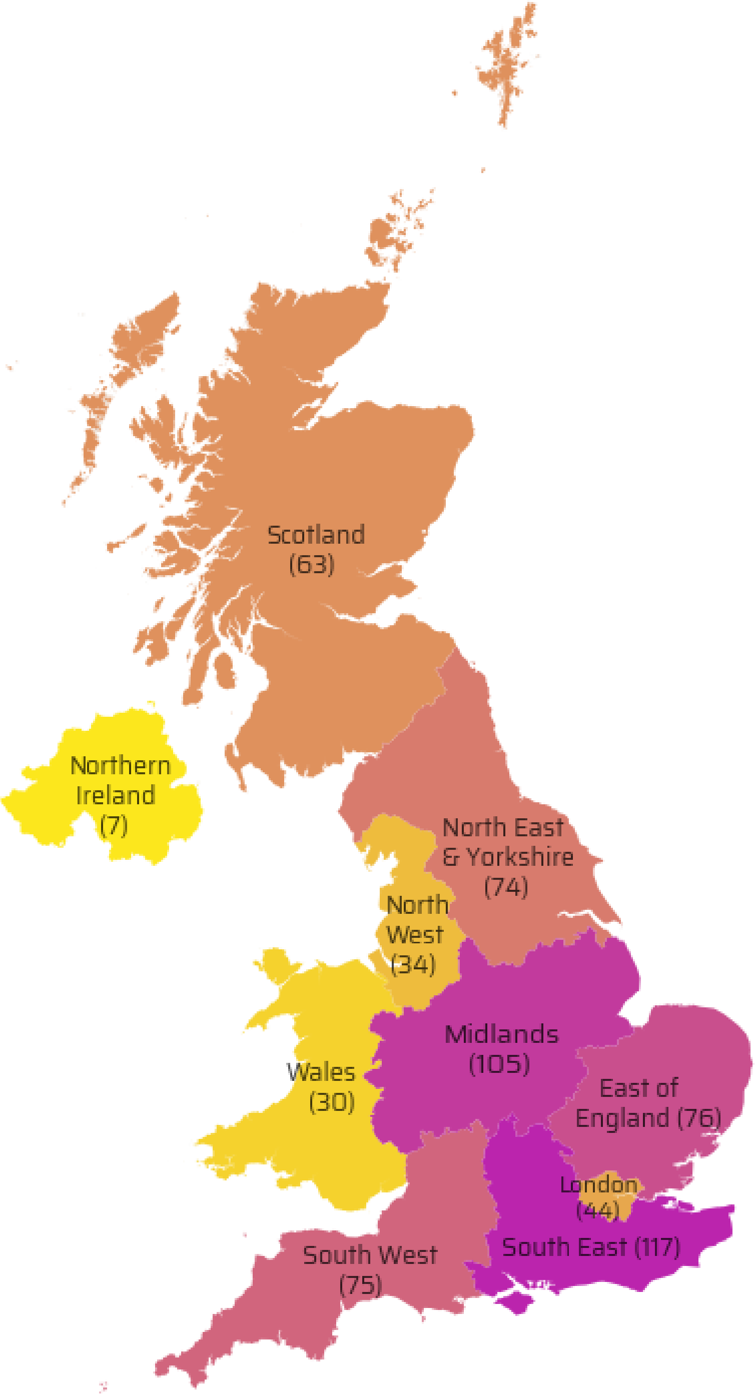


Figure 46 Location of the respondents.

Table 43 Location of the respondents.

Regions	Respondents	Percentage
Southeast	117	18.63
Midlands	105	16.72
East of England	76	12.1
Southwest	75	11.94
Northeast and Yorkshire	74	11.78
Scotland	63	10.03
London	44	7.01
Northwest	34	5.41
Wales	30	4.78
Northern Ireland	7	1.11
Isle of Man	3	0.48

NB: The regions in England are further divided into 'NHS England Regions'. We asked respondents for the first part of their postcodes. 32 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. 89 respondents did not provide their postcodes or offered invalid postcodes, and therefore were not included in this analysis.

Employment status.

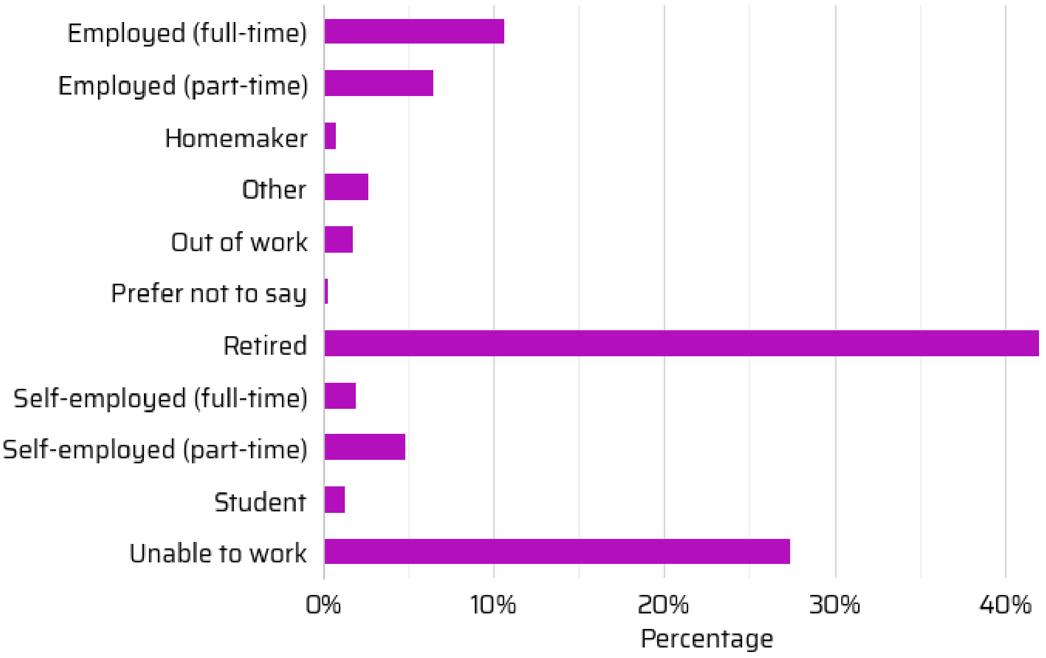


Figure 47 Employment status of respondents.

Table 44 Employment status of respondents.

Employment status	Respondents	Percentage
Employed (full-time)	73	10.66
Employed (part-time)	44	6.42
Homemaker	5	0.73
Other	18	2.63
Out of work	12	1.75
Prefer not to say	2	0.29
Retired	288	42.04
Self-employed (full-time)	13	1.9
Self-employed (part-time)	33	4.82
Student	9	1.31

Unable to work	188	27.45

Number of dependents

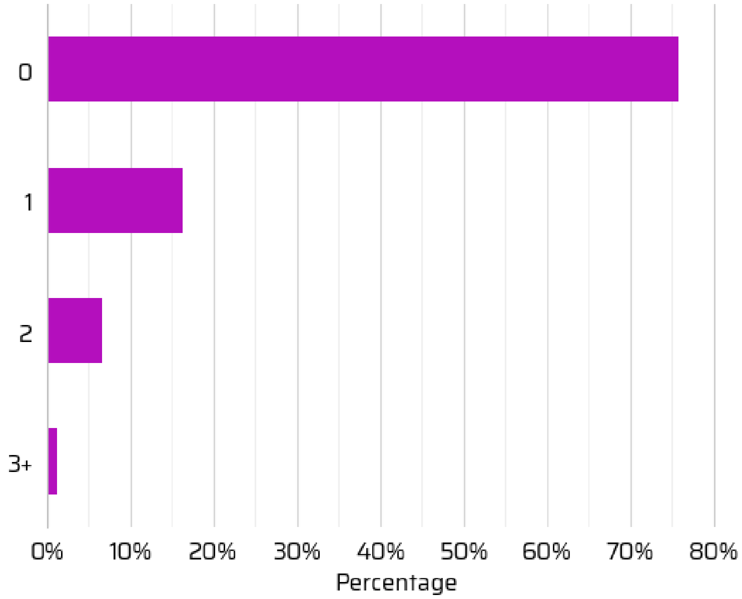


Figure 48 Number of dependents of respondents.

Table 45 Number of dependents of respondents.

Number of dependents	Respondents	Percentage
0	519	75.77
1	112	16.35
2	46	6.72
3+	8	1.17

Receiving care or support

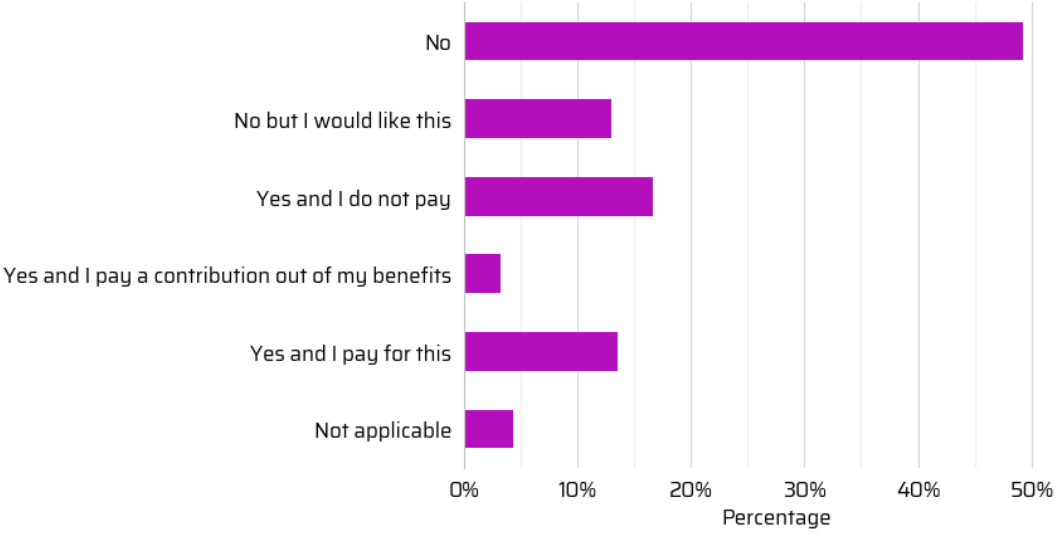


Figure 49 Whether respondents receiving care or support.

Table 46 Whether respondents receiving care or support.

Receive care/support	Respondents	Percentage
No	337	49.2
No but I would like this	89	12.99
Yes and I do not pay	114	16.64
Yes and I pay a contribution out of my benefits	22	3.21
Yes and I pay for this	93	13.58
Not applicable	30	4.38

Appendix A – Survey Questions

Question	**Response options**	
Are you filling in this questionnaire for yourself?	Yes	No
About your condition(s) The next few questions are about your neurological condition(s). By sharing your condition(s) and symptoms with us, we can identify variation in care and support.		
Which year were you diagnosed with your primary neurological condition?	Free text	
Please tell us which neurological condition you were first diagnosed with.	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: This means any other long-term condition which is not neurological. It might include conditions related to your mental health, heart, lungs or joints.	None	1	2	3
	4	5	6+	
Have the NHS strikes affected you? The next couple of questions are focused on how the NHS strikes have affected you.				
Have the NHS strikes had an impact on your healthcare and support this year?	Yes			
	I am not sure			
	No			
	Not applicable			
How have the strikes had an impact on your healthcare and support?	Free text			
Heading into Winter Autumn and Winter can pose specific challenges for people with neurological conditions. These include additional pressures on health and care services and changing temperatures impacting neurological symptoms and conditions. We would like to understand what your concerns are and how your needs may change.				
What are your biggest concerns as we head into Winter?	Free text			
Will your care, support or information needs change in the next 6 months?	Yes	No	I am not sure	
How do you believe the care, support or information that you receive needs to change?	Free text			
About your recent experiences of treatment and support				

We would like you to rate the quality of care and support services that you have used recently. This includes specialist NHS care, emergency care (e.g. via A&E), social care or support from your GP.				
Have you accessed health or care (from the NHS, a care provider and/or privately) in the past eight weeks?	Yes	No		
Overall, how would you describe your experience of health or care in the last eight weeks?	Very Good	Good	Average	Poor
	Very Poor	N/A		
How many times have you sought A&E/emergency support from the NHS as a result of your neurological condition in the last eight weeks?	None			
	1-2 times			
	3-5 times			
	5 or more times			
Have you had any medical appointments (including remote appointments) in the last eight weeks?	Yes	No	Don't know	
How many medical appointments have you had in the last 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
	Diagnostics services (e.g. a radiologist, physiologist)
	Rehabilitation service
	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
	Diagnostic services (e.g. a radiologist, physiologist)
	Rehabilitation service
	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

	Diagnostic services (e.g. a radiologist, physiologist)
	Rehabilitation service
	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

	Diagnostic services (e.g. a radiologist, physiologist)
	Rehabilitation service
	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

	Diagnostic services (e.g. a radiologist, physiologist)
	Rehabilitation service
	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

	Diagnostic services (e.g. a radiologist, physiologist)
	Rehabilitation service
	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

Quality of life and wellbeing

We know that having a neurological condition(s) affect all aspects of a person's life.

These next questions look to capture how your life and wellbeing are affected.

Which of the following describes how you feel at the moment? Please select all that apply.	Calm
	Well supported

	Anxious
	Hopeless
	Lonely
	Other
What other words would you use to describe how you feel at the moment?	Free text
To what extent is your quality of life affected by your neurological condition?	To a great extent
	To a large extent
	Somewhat
	A little
	Not at all
Please explain how your quality of life is impacted by your neurological condition(s)	Free text
About you The following questions help us to identify any potential variation in the daily realities, care, and support, while also aiding us in striving to be as representative as possible.	
What is your age range?	Under 18 years of age
	18 to 24 years of age
	25 to 34 years of age
	35 to 44 years of age
	45 to 54 years of age
	55 to 64 years of age
	65 to 69 years of age
	Over 70 years of age

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
	4
	5
	6+
Do you receive any care or support at home for your day-to-day life?	Yes and I pay for this

<table>
<tr><td rowspan="5"></td><td>Yes and I pay a contribution out of my benefits</td></tr>
<tr><td>Yes and I do not pay</td></tr>
<tr><td>No but I would like this</td></tr>
<tr><td>No</td></tr>
<tr><td>Not applicable</td></tr>
<tr><td colspan="2">**Communicating with you.**
If you are happy to hear from us about how your support is benefitting people affected by neurological conditions, please complete the following questions.
You can stop receiving communications or change any of your preferences at any time by contacting us at: info@neurolifenow.org.
For full details of what information, we hold and how we process your data, please see our privacy policy.</td></tr>
<tr><td>What is your first name?</td><td>Free text</td></tr>
<tr><td>What is your surname?</td><td>Free text</td></tr>
<tr><td>What is your Email Address?</td><td>Free text</td></tr>
<tr><td>What is the first line of your address?</td><td>Free text</td></tr>
<tr><td>What is your postcode?</td><td>Free text</td></tr>
</table>

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	Cerebellar tremor
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	Dystonic tremor	Eaton-Lambert syndrome
Ehlers Danlos Syndromes	Encephalitis	Enhanced physiologic tremor
Epidemic vertigo	Epilepsy	Essential tremor
Extradural and subdural abscess	Extrapyramidal disorder	Facial myokymia
Faetal Alcohol Spectrum Disorders (FASD)	Fatal Familial Insomnia syndrome	Fibromyalgia
Functional Neurological Disorder	Functional tremor	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	Intraspinal abscess and granuloma
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	Orthostatic Tremor
Orthostatic tremor	Papilloedema	Paraplegia and tetraplegia
Parkinsonian tremor	Parkinsonism	Peripheral Neuropathy
Pernicious Anaemia	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