



NeuroLifeNow

March - April 2023 Survey Report
Your priorities for the NHS

**Brain & Spine
Foundation**

 **THE
NEUROLOGICAL
ALLIANCE**

 **COMMUNITY
FUND**

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Foreword

Waiting. That is perhaps the daily reality of most people affected by neurological conditions right now, as they wait to access the right treatment, care and support. Since the start of the pandemic, the NHS neurology waiting list in England has more than doubled, but not the investment and workforce to deliver those services. In this context, it is easy to see why people are waiting, but it does not make it less stressful or devastating.

“I haven’t seen my Dr for 5 years and even then she said my unsteadiness & falling over were vit D deficiency. I felt it was me being Lazy why I was getting weaker. If it hadn’t been for phoning and speaking to nurses practitioner I would never have been referred to a neurologist. By time I got Anti-MAG diagnosis, much of my nerve damage is irreversible.”

In our latest survey, we delved deeper into people's daily realities of waiting and accessing care. Two thirds of people told us that they disagreed with the statement "While I wait for the treatment and care that I need, I am kept informed and feel supported", with nearly a third saying they strongly disagreed. People with multiple neurological conditions, females, and those not in employment were more likely to disagree.

More than 4 out of 10 people told us they couldn't see a specialist when they needed to - this was for a variety of reasons, including the fact that they couldn't book ahead, cancellations to their existing appointments, a lack of specialists with the right expertise or just waiting to see someone.

We also wanted to know more about what people needed from the NHS. Treatment, care and support for people affected by neurological conditions has changed dramatically. We now know more on how to treat many neurological conditions in a better way - the challenge is making sure we have the people and services in place so people can access support.

Your message was clear - you want to see an NHS where staff know more about neurological conditions, shortened waiting times, action to tackle overstretched staff and measures to make it easier to see your GP.

“Because the staff are so stretched, it makes it hard to do what they need. So the way things are run need to be sorted to help everyone”

The NHS turned 75 in July, and we are heading into a General Election in the next 18 months. We will be calling on leaders across the UK to do all they can to address these priorities. People with neurological conditions have waited too long.

The Brain & Spine Foundation neuroscience nurses are here for you, providing practical and emotional support relating to any neurological condition(s). You can get in touch for free by calling **0808 808 1000** (Mon-Fri, 9am - 4pm) or email helpline@brainandspine.org.uk.

Thank you so much.

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

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Background

NeuroLifeNow is a platform designed to support people's conditions to share their daily realities of living with neurological conditions. Insights are shared with NHS Commissioners, UK Governments, and clinicians to influence how neurological services are delivered and to drive positive change.

This report focuses on the findings of the survey running over March and April 2023. Along with the health and care related questions we ask about consistently to monitor change over time, this survey focused on finding out about your priorities for the NHS, and access to care and support services.

Key Findings

- 283 respondents completed the March-April 2023 survey, with 65 conditions represented. The top 3 most frequently reported conditions are Dystonia, Functional Neurological Disorder and Chiari Malformation.
- Nearly half (48.41%) of people disagreed with the statement "I feel listened to by my health and care professionals".
- Nearly 4 out of 10 (39.22%) said they disagreed with the statement "I know who to contact if I have a question about my neurological condition or if it changes".
- 66.79% of people disagreed that "While I wait for the treatment and care that I need, I am kept informed and feel supported".
- Females were less likely to agree with all statements, as were those with multiple neurological conditions.
- When respondents did speak to a specialist, 84.82% said it was convenient to do so. 6.35% said it was not at all convenient.
- When people were not able to speak to a specialist when they wanted to, 46.64% went without any support, 27.92% went to an appointment in the future, and 11.31% had a consultation over the phone. 1.77% went to A&E or a walk-in centre.
- 63.96% of respondents had access to medical appointments in the last eight weeks. 65.02% were found to be helpful (down from three quarters in January and February). Most people had one or two appointments in the past 8 weeks.

- 35.33% said they felt their experience of healthcare in the past 8 weeks had been poor or very poor.

Priorities for the NHS

Priorities for the NHS: overall

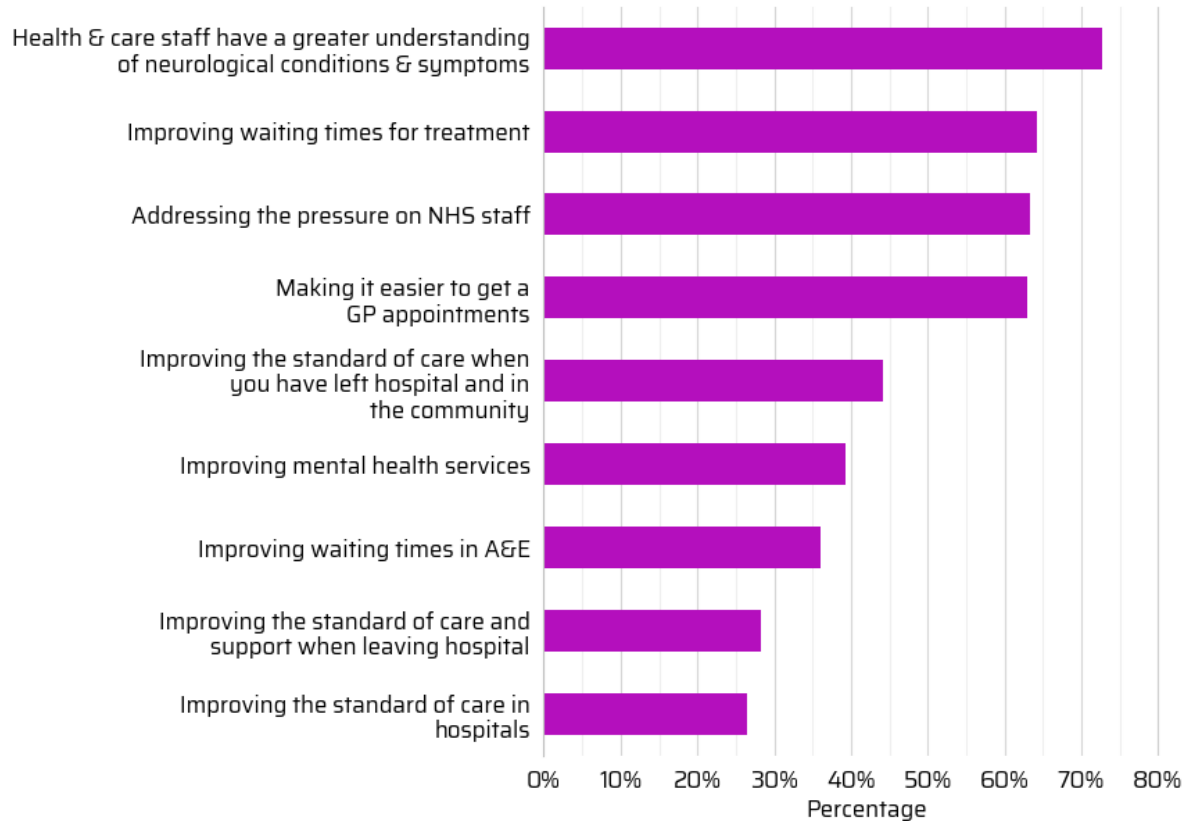


Figure 1 : Priorities for the NHS: overall.

Table 1: Priorities for the NHS: overall.

NHS priorities	Respondents	Percentage
Health & care staff have a greater understanding of neurological conditions & symptoms	206	72.79
Improving waiting times for treatment	182	64.31
Addressing the pressure on NHS staff	179	63.25
Making it easier to get a GP appointment	178	62.9
Improving the standard of care when you have left hospital and, in the community,	125	44.17

Improving mental health services	111	39.22
Improving waiting times in A&E	102	36.04
Improving the standard of care and support when leaving hospital	80	28.27
Improving the standard of care in hospitals	75	26.5

Priorities for the NHS: other priorities

In the survey, respondents were asked what their priorities are for the NHS. One of the options was “other”, and the following are the list of priorities given in the form of free text:

1. Continuity of care
2. Improve quality of NHS staff (e.g., improve cultural competency, more specialists)
3. Better access to healthcare (e.g., home visits from GP)
4. Personalised healthcare
5. Regular monitoring of rare disorders
6. Integrated and holistic healthcare or support services (e.g., between GP and hospitals)
7. Mental health assessment for neurological conditions
8. Listen to the patient.

Priorities for the NHS: reasons for choosing different priorities.

We asked the reasons why respondents chose the priorities listed or what they have written down in the “other” section. A word cloud was generated from the responses.

- **Theme 3: Lack of support**
 - Lack of support after discharge or diagnosis
 - Feeling abandoned
- **Theme 4: Overstretched NHS system**
 - NHS staff need more support to ease their pressure.
 - NHS is under-resourced and needs to be restructured.
- **Theme 5: Lack of awareness of neurological conditions**
- **Theme 6: Poor communications among health professionals**

Theme 1: Experience of having neurological conditions.

Respondents have reported that they selected the priorities in the survey based on lived experience of having neurological conditions. This mainly reflects the sufferings the patients must go through. They also had poor health service experiences, especially at the A&E. The main motivations behind their selection of priorities were what they considered important and relevant.

“Patients are suffering.”

“The NHS is in crisis and we are all suffering.”

“Without these improvements, it is what is keeping me permanently covered in multiple old and new head and body injuries. My worst injury is more than 6 months old and still has not recovered any treatment....”

Based on personal or peers’ experience

“My answers are based on my own personal experiences.”

“Because I provide peer-peer psycho education where people always talk about these issues and have experienced them myself.”

Poor health service experience

“My recent personal experience: 11 hours in A&E; another 2 hours to be further assessed by a doctor and admitted; 3 weeks in the Emergency Assessment Unit with no windows, no way of getting out (had lost use of left limbs within days of admission), two patients in bay had severe dementia with challenging behaviours and should never have been there.”

“After having to spend a night in A&E it was a very scary experience when they seemed to have literally no idea about my condition.”

“The poor quality of my neurological care and the way this impacts on my quality of life.”

“They are relevant and a true reflection. I was in a & e after arriving by ambulance when the brain hemorrhage occurred. I was not scanned and told I had a hemiplegic migraine. I had stroke symptoms down my left side and double vision. After I left a & e 2 days later I sought more help, was given an MRI and told I had an AVM which had ruptured and caused the brain hemorrhage. My GP as great as they are, are clueless about AVM, one even told me it was above his pay grade.”

“The neuro rehab team refused to see him after 2 urgent referrals which resulted in us having to pay for a private specialist to visit him. The district nurses have refused to visit him, it took over a month to get a mattress delivered to prevent bedsores when he was completely bed bound.”

Importance and relevance

“Because they matter for people living with rare neurological conditions as well as more common ones.”

“They have the greatest impact on my life.”

“These seem to be the most urgent.”

Theme 2: Long waiting time

Long waiting time, lack of regular appointments, difficulty in getting appointments and appointment time being too short were also listed as the reasons that motivated the respondents to pick the priorities they have chosen.

“Waiting times for treatment have to be improved as people are losing their lives.”

“Waiting for help for nearly 2 years for a brain condition is not acceptable!”

“Waiting times for A&E and hospital appointments are way too long, it causes more damage and deterioration in health.”

“I haven’t seen my Dr for 5 years and even then she said my unsteadiness & falling over were vit D deficiency. I felt it was me being Lazy why I was getting weaker. If it hadn’t been for phoning and speaking to nurses practitioner I would never have been referred to a neurologist. By time I got Anti-MAG diagnosis, much of my nerve damage is irreversible.”

“I moved 15 months ago and I am still waiting to see a PD nurse. Prior to the move, due to Covid, I had not seen a PD nurse for 25 months. Had lots of appointments cancelled but a wait of nearly 3 1/2 years is unacceptable.”

“Trying to get a gp appointment and then trying to deal with multiple complex conditions in that 10 minute appointment is impossible.”

Theme 3: Lack of support

This theme reflects the poor aftercare and community care after respondents' diagnosis or discharge. This lack of support made them feel abandoned and impacted their mental health.

Lack of support after discharge or diagnosis

“There is a lack of care once you are back in the community. Follow up for chiari malformation is practically non-existent.”

“I feel the service of care when you are in hospital is often second to none, but the minute you are discharged, your on your own.”

“Feel that once you are diagnosed or put on a course of medication you are then left to your own devices. There is not follow up unless the patient continues to contact the practitioner/doctor?”

“...should receive care and support for a lifetime as other conditions, such as heart failure, do. Better, appropriate investment in health and care from day one and continuously throughout your life would save money and resources in the long term.

Allowing those with a Neurological Condition to continue to make a valuable contribution to Society.”

Feeling abandoned

“I know I feel abandoned, slowly deteriorating. Sometimes, instead of having to , I just want to feel looked after for a change.”

“I felt completely dumped by the Hospital post op. A phone call for physio after spinal surgery for a spinal surgery. Letter to GP from surgeon took 3 months to arrive. I only found about a local gym's hydrotherapy pool by chance”

“Because once I was diagnosed I felt “kicked to the kerb” and left to get on with it.”

“I feel I have very little support from GP and my Neurologist has never really explained very much about my condition”

“We are not listened to, not treated with courtesy and respect, basically ignored in favour of people (and I quote)” with a real medical condition”

“The gaslighting is causing me depression and more CBT is obv not the answer to that! The level of misogyny and ignorance is astounding.”

Theme 4: Overstretched NHS

Another reason respondents cited is that NHS is overstretched, with their staff needing more support to ease their pressure. Given that NHS is under-resourced, some also expressed that it needs to be restructured.

NHS staff need more support to ease their pressure

“We need to recognise burn out in our doctors and nurses.”

“Nhs staff have worked very hard over the past 4 years and many are exhausted.”

“If you take care of staff they can take care of people not numbers.”

“Because the staff are so stretched it makes it hard to do what they need. So the way things are run need to be sorted to help everyone”

NHS is under-resourced and needs to be restructured.

“The NHS is underfunded and under resourced. The staff are unable to supply the care which we, the public need.”

“The fact that so much of the NHS provision is now outsourced, and that private companies are making a profit from a public service is scandalous.”

“Without doubt people are trying hard but services are overstretched and therefore overwhelmed and something major needs to happen to prevent the government from using this to privatise the NHS.”

“The system is failing and going under. Immediate help is needed. There is no point further educating about condition if its virtually impossible to see a doctor/specialist anyway.”

“We need a service that works for everyone, we once had a world leading healthcare system and now it’s in death throes.”

Theme 5: Lack of awareness of neurological conditions

There is also a lack of awareness and understanding of neurological conditions. This is reflected by the lack of training for health professionals.

“Staff are poorly trained in neurology & dismiss cognitive impairments beyond dementia -I don't have dementia but executive cognitive impairments & showing a sheet given by my NEURO OT on this or my headway card to explain my communication difficulties not respected or protected-especially during covid when I couldn't have a care with me.”

“NHS staff have to have a greater understanding of traumatic brain injury, although it is very difficult with invisible disabilities.”

“Currently I am being told by several practitioners that my conditions aren't real and that all I have is health anxiety. This has had horrendous ramifications as I am being denied care in my old age. Thankfully my GP understands and supports me but he's not an expert on my conditions.”

“Even though it is a chronic & progressive spinal cord injury, because it is incomplete, it is not well understood by my GP, Spinal Nurse Specialists or my neurosurgeon.”

“I waste 90% of my time at appointments explaining my rare condition before I can get to the reason why I'm there.”

” Perhaps awareness, more empathy, understanding and patience could be offered by those especially those working in a neurological setting.”

“Sending you off with a miss diagnosis is not better than actually finding the cause of your actual illness.”

Theme 6: Poor communications among health professionals

Another theme that emerged is that there is poor communication among health professionals. The respondents expressed that a more holistic and personalised approach is needed.

“Also think there needs to be better communication between health departments so that they are kept informed about my health care - in an ideal world the GP would be the person coordinating and ensuring a seamless service so that you are treated as a whole person. It is frustrating that doctors don't communicate and share insight into your health and care issues.”

“co-ordination between GPs and specialists appears limited and disjointed- I have barely seen a doctor since 2019 and can only speak to a neurological consultant through a GP referral. If they then don't see a problem on a CT scan, I'm referred back to my GP to live in pain/exhaustion and with limited mobility.”

” I really need specialised care that’s absolutely tailored to my needs, and I also need for it to be easy to access. I’m struggling with things such as getting to appointments and then finding it was not worthwhile because of the gaslighting trend amongst insincere and arrogant medical practitioners. My conditions aren’t even rare!“

“The communication between different hospital departments and GP’s surgeries does not fill me with confidence. There needs to be a more holistic approach and way that information is passed around.”

“Different people have said different things about my medical health, which is very frustrating and annoying at the same time.”

Access to health and care

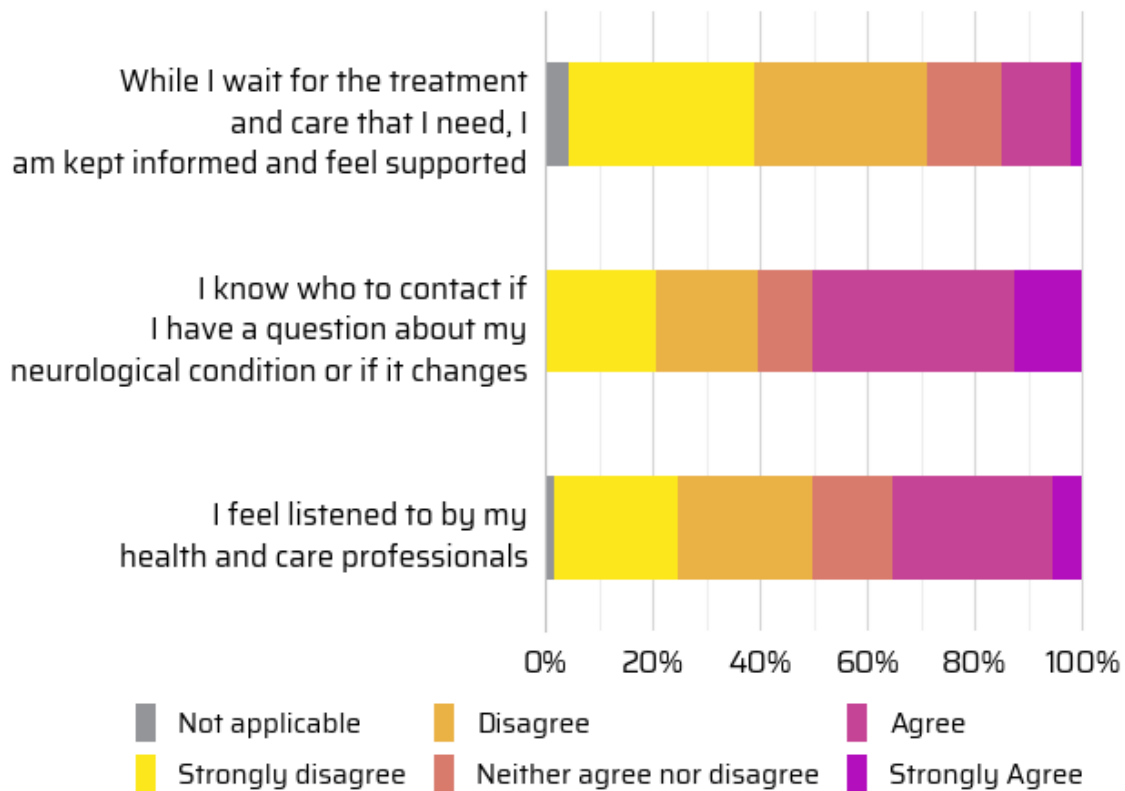


Figure 3 : Overall experience of health and care.

Table 2 : Overall experience of health and care.

Healthcare experience	Response	Respondents	Percentage
I feel listened to by my health and care professionals	Strongly Agree	16	5.65
	Agree	84	29.68

	Neither agree nor disagree	42	14.84
	Disagree	71	25.09
	Strongly disagree	66	23.32
	Not applicable	4	1.41
	Strongly Agree	36	12.72
	Agree	106	37.46
I know who to contact if I have a question about my neurological condition or if it changes	Neither agree nor disagree	29	10.25
	Disagree	54	19.08
	Strongly disagree	57	20.14
	Not applicable	1	0.35
	Strongly Agree	6	2.12
	Agree	36	12.72
While I wait for the treatment and care that I need, I am kept informed and feel supported	Neither agree nor disagree	40	14.13
	Disagree	91	32.16
	Strongly disagree	98	34.63
	Not applicable	12	4.24

Access to health and care: with vs without multiple neurological conditions

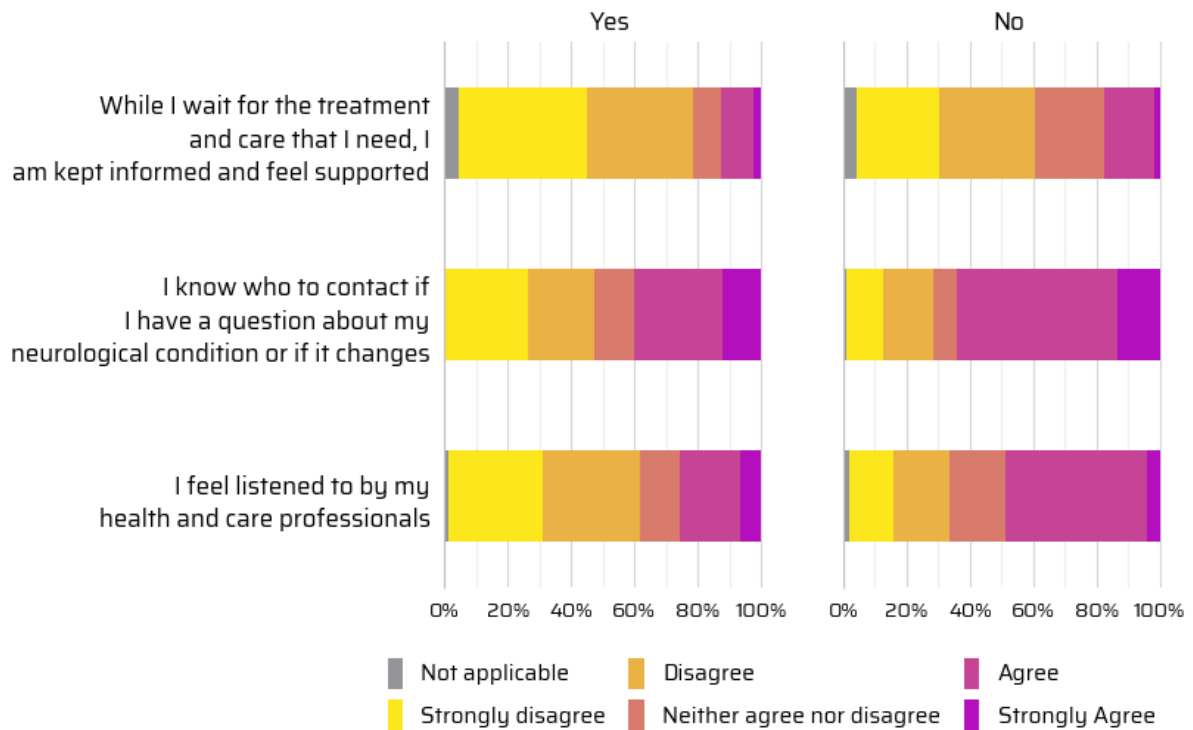


Figure 4 : Experience in health and care among people with vs without multiple neurological conditions.

Table 3 : Experience in health and care among people with vs without multiple neurological conditions.

Multiple neurological conditions	Healthcare experience	Response	Respondents	Percentage
Yes	I feel listened to by my health and care professionals	Strongly Agree	11	6.71
		Agree	31	18.9
		Neither agree nor disagree	21	12.8
		Disagree	50	30.49
		Strongly disagree	49	29.88
		Not applicable	2	1.22
	I know who to contact if I have a question about my	Strongly Agree	20	12.2
		Agree	46	28.05

No	neurological condition or if it changes	Neither agree nor disagree	20	12.2
		Disagree	35	21.34
		Strongly disagree	43	26.22
		Not applicable	0	0.0
	While I wait for the treatment and care that I need, I am kept informed and feel supported	Strongly Agree	4	2.44
		Agree	17	10.37
		Neither agree nor disagree	14	8.54
		Disagree	55	33.54
	I feel listened to by my health and care professionals	Strongly disagree	67	40.85
		Not applicable	7	4.27
		Strongly Agree	5	4.2
		Agree	53	44.54
	I know who to contact if I have a question about my neurological condition or if it changes	Neither agree nor disagree	21	17.65
		Disagree	21	17.65
Strongly disagree		17	14.29	
Not applicable		2	1.68	
While I wait for the treatment and care that I need, I am kept informed and feel supported	Strongly Agree	16	13.45	
	Agree	60	50.42	
	Neither agree nor disagree	9	7.56	
	Disagree	19	15.97	
	Strongly disagree	14	11.76	
	Not applicable	1	0.84	
	Strongly Agree	2	1.68	
	Agree	19	15.97	
	Neither agree nor disagree	26	21.85	

Disagree	36	30.25
Strongly disagree	31	26.05
Not applicable	5	4.2

Access to health and care: with vs without co-occurring non-neurological conditions.

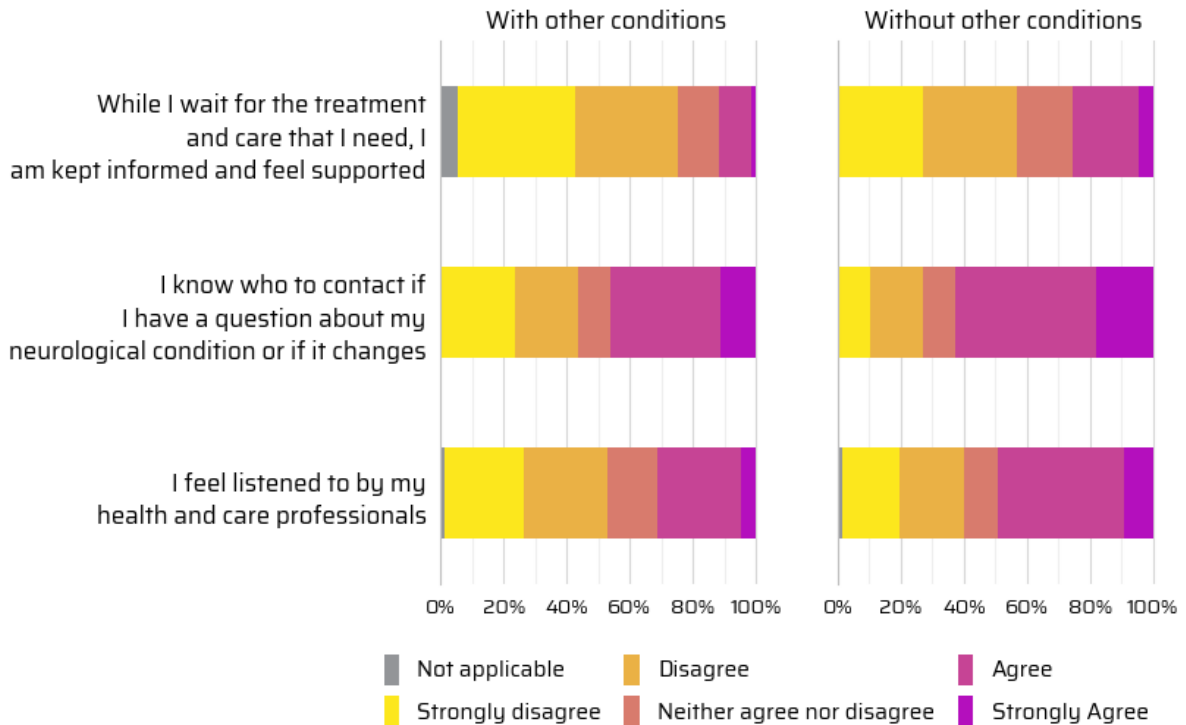


Figure 5 : Experience in health and care among people with vs without co-occurring non-neurological conditions.

Table 4 : Experience in health and care among people with vs without co-occurring non-neurological conditions.

Co-occurring conditions	Healthcare experience	Response	Respondents	Percentage
With other conditions	I feel listened to by my health and care professionals	Strongly Agree	10	4.63
		Agree	57	26.39
		Neither agree nor disagree	35	16.2
		Disagree	57	26.39

	Strongly disagree	54	25.0
	Not applicable	3	1.39
	Strongly Agree	24	11.11
	Agree	76	35.19
I know who to contact if I have a question about my neurological condition or if it changes	Neither agree nor disagree	22	10.19
	Disagree	43	19.91
	Strongly disagree	50	23.15
	Not applicable	1	0.46
While I wait for the treatment and care that I need, I am kept informed and feel supported	Strongly Agree	3	1.39
	Agree	22	10.19
	Neither agree nor disagree	28	12.96
	Disagree	71	32.87
	Strongly disagree	80	37.04
Without other conditions	Not applicable	12	5.56
	Strongly Agree	6	8.96
	Agree	27	40.3
	Neither agree nor disagree	7	10.45
	Disagree	14	20.9
I feel listened to by my health and care professionals	Strongly disagree	12	17.91
	Not applicable	1	1.49
	Strongly Agree	12	17.91
	Agree	30	44.78
	Neither agree nor disagree	7	10.45
I know who to contact if I have a question about my neurological condition or if it changes	Disagree	11	16.42
	Strongly disagree	7	10.45

	Not applicable	0	0.0
	Strongly Agree	3	4.48
	Agree	14	20.9
While I wait for the treatment and care that I need, I am kept informed and feel supported	Neither agree nor disagree	12	17.91
	Disagree	20	29.85
	Strongly disagree	18	26.87
	Not applicable	0	0.0

Access to health and care: age groups

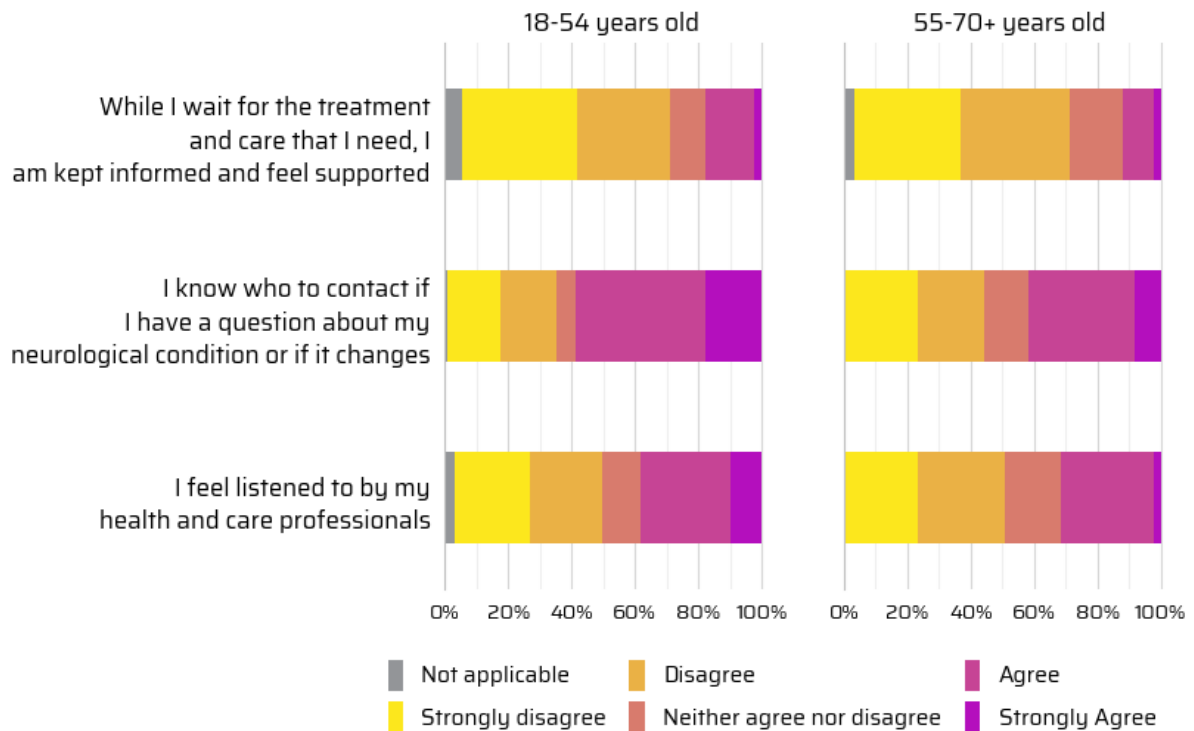


Figure 6 : Experience in health and care among people in different age groups.

Table 5 : Experience in health and care among people in different age groups.

Age	Healthcare experience	Response	Respondents	Percentage
55-70+		Strongly Agree	3	2.01
		Agree	44	29.53

	Neither agree nor disagree	26	17.45
I feel listened to by my health and care professionals	Disagree	41	27.52
	Strongly disagree	35	23.49
	Not applicable	0	0.0
	Strongly Agree	12	8.05
	Agree	50	33.56
I know who to contact if I have a question about my neurological condition or if it changes	Neither agree nor disagree	21	14.09
	Disagree	31	20.81
	Strongly disagree	35	23.49
	Not applicable	0	0.0
	Strongly Agree	3	2.01
	Agree	15	10.07
While I wait for the treatment and care that I need, I am kept informed and feel supported	Neither agree nor disagree	25	16.78
	Disagree	51	34.23
	Strongly disagree	50	33.56
	Not applicable	5	3.36
	Strongly Agree	13	9.92
	Agree	37	28.24
I feel listened to by my health and care professionals	Neither agree nor disagree	16	12.21
	Disagree	30	22.9
18-54	Strongly disagree	31	23.66
	Not applicable	4	3.05
I know who to contact if I have a question about my neurological condition or if it changes	Strongly Agree	23	17.56
	Agree	54	41.22
	Neither agree nor disagree	8	6.11

	Disagree	23	17.56
	Strongly disagree	22	16.79
	Not applicable	1	0.76
	Strongly Agree	3	2.29
	Agree	20	15.27
	Neither agree nor disagree	15	11.45
While I wait for the treatment and care that I need, I am kept informed and feel supported	Disagree	38	29.01
	Strongly disagree	48	36.64
	Not applicable	7	5.34

Access to health and care: gender

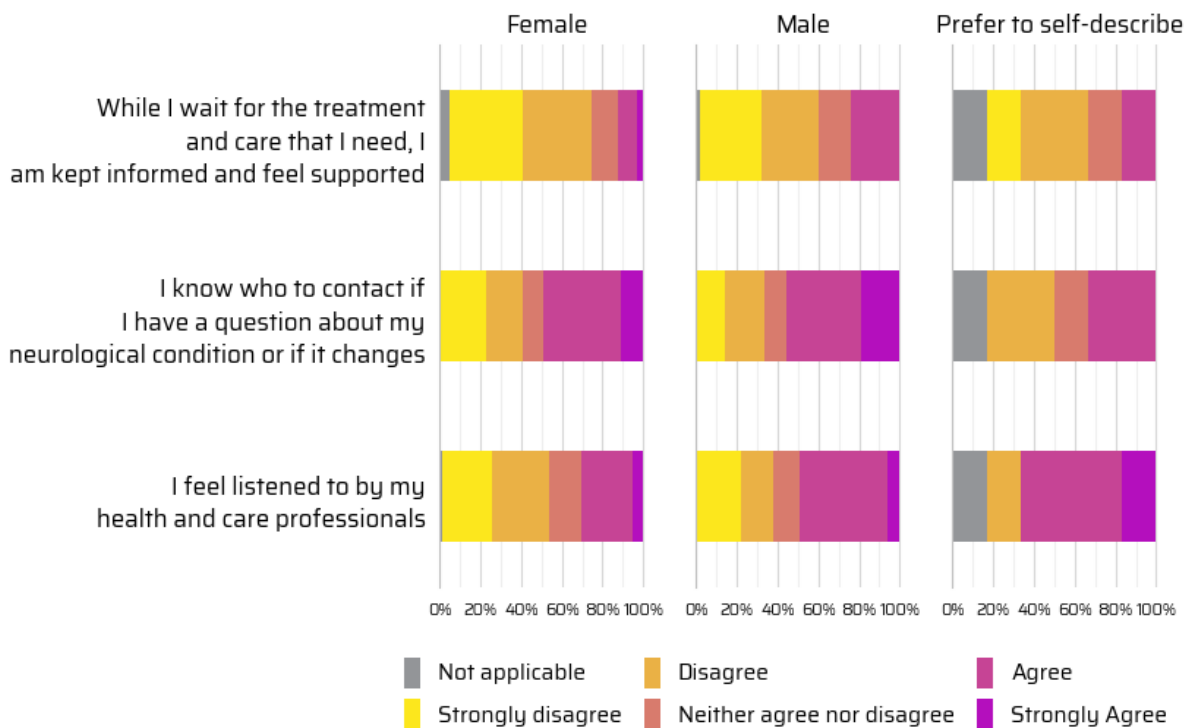


Figure 7 : Experience in health and care among people in different genders.

Table 6 : Experience in health and care among people in different genders.

Gender	Healthcare experience	Response	Respondents	Percentage
Female	I feel listened to by my health and care professionals	Strongly Agree	11	5.14
		Agree	54	25.23
		Neither agree nor disagree	34	15.89
		Disagree	60	28.04
		Strongly disagree	52	24.3
		Not applicable	3	1.4
	I know who to contact if I have a question about my neurological condition or if it changes	Strongly Agree	24	11.21
		Agree	81	37.85
		Neither agree nor disagree	21	9.81
		Disagree	40	18.69
		Strongly disagree	48	22.43
		Not applicable	0	0.0
	While I wait for the treatment and care that I need, I am kept informed and feel supported	Strongly Agree	6	2.8
		Agree	20	9.35
		Neither agree nor disagree	29	13.55
		Disagree	71	33.18
		Strongly disagree	78	36.45
		Not applicable	10	4.67

		Strongly Agree	4	6.35
		Agree	27	42.86
	I feel listened to by my health and care professionals	Neither agree nor disagree	8	12.7
		Disagree	10	15.87
		Strongly disagree	14	22.22
		Not applicable	0	0.0
		Strongly Agree	12	19.05
		Agree	23	36.51
	I know who to contact if I have a question about my neurological condition or if it changes	Neither agree nor disagree	7	11.11
Male		Disagree	12	19.05
		Strongly disagree	9	14.29
		Not applicable	0	0.0
		Strongly Agree	0	0.0
		Agree	15	23.81
	While I wait for the treatment and care that I need, I am kept informed and feel supported	Neither agree nor disagree	10	15.87
		Disagree	18	28.57
		Strongly disagree	19	30.16
		Not applicable	1	1.59
	I feel listened to by my health and care professionals	Strongly Agree	1	16.67

Access to health and care: employment status

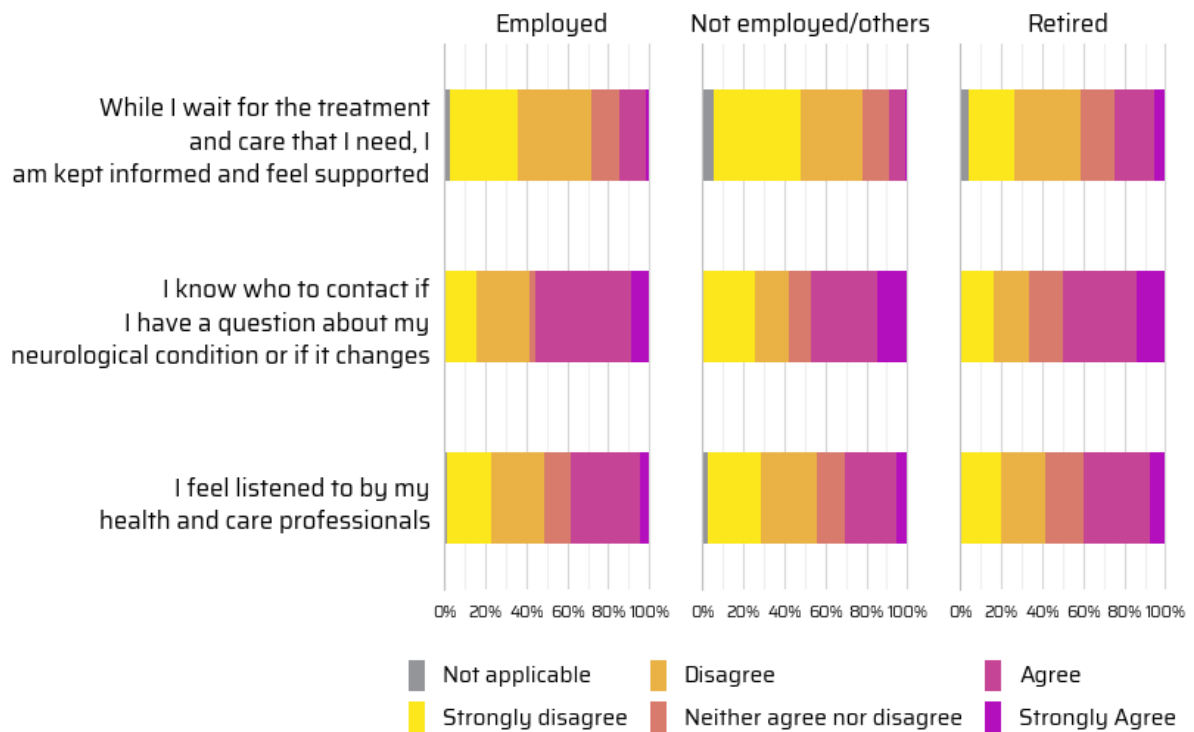


Figure 8 : Experience in health and care among people in different employment status.

Table 7 : Experience in health and care among people in different employment status.

Employment status	Healthcare experience	Response	Respondents	Percentage
Not employed /Others	I feel listened to by my health and care professionals	Strongly Agree	7	5.26
		Agree	34	25.56
		Neither agree nor disagree	18	13.53
		Disagree	36	27.07
		Strongly disagree	35	26.32
		Not applicable	3	2.26
	I know who to contact if I have a question about my neurological condition or if it changes	Strongly Agree	19	14.29
		Agree	44	33.08
		Neither agree nor disagree	14	10.53
		Disagree	22	16.54

	Strongly disagree	33	24.81
	Not applicable	1	0.75
	Strongly Agree	1	0.75
	Agree	11	8.27
While I wait for the treatment and care that I need, I am kept informed and feel supported	Neither agree nor disagree	17	12.78
	Disagree	40	30.08
	Strongly disagree	57	42.86
	Not applicable	7	5.26
	Strongly Agree	3	4.29
	Agree	24	34.29
	Neither agree nor disagree	9	12.86
I feel listened to by my health and care professionals	Disagree	18	25.71
	Strongly disagree	15	21.43
	Not applicable	1	1.43
	Strongly Agree	6	8.57
	Agree	33	47.14
Employed I know who to contact if I have a question about my neurological condition or if it changes	Neither agree nor disagree	2	2.86
	Disagree	18	25.71
	Strongly disagree	11	15.71
	Not applicable	0	0.0
	Strongly Agree	1	1.43
While I wait for the treatment and care that I need, I am kept informed and feel supported	Agree	9	12.86
	Neither agree nor disagree	10	14.29
	Disagree	25	35.71
	Strongly disagree	23	32.86

		Not applicable	2	2.86
		Strongly Agree	6	7.5
		Agree	26	32.5
	I feel listened to by my health and care professionals	Neither agree nor disagree	15	18.75
		Disagree	17	21.25
		Strongly disagree	16	20.0
		Not applicable	0	0.0
		Strongly Agree	11	13.75
		Agree	29	36.25
	I know who to contact if I have a question about my neurological condition or if it changes	Neither agree nor disagree	13	16.25
		Disagree	14	17.5
		Strongly disagree	13	16.25
		Not applicable	0	0.0
		Strongly Agree	4	5.0
		Agree	16	20.0
	While I wait for the treatment and care that I need, I am kept informed and feel supported	Neither agree nor disagree	13	16.25
		Disagree	26	32.5
		Strongly disagree	18	22.5
		Not applicable	3	3.75

Access to health and care: with vs without dependents

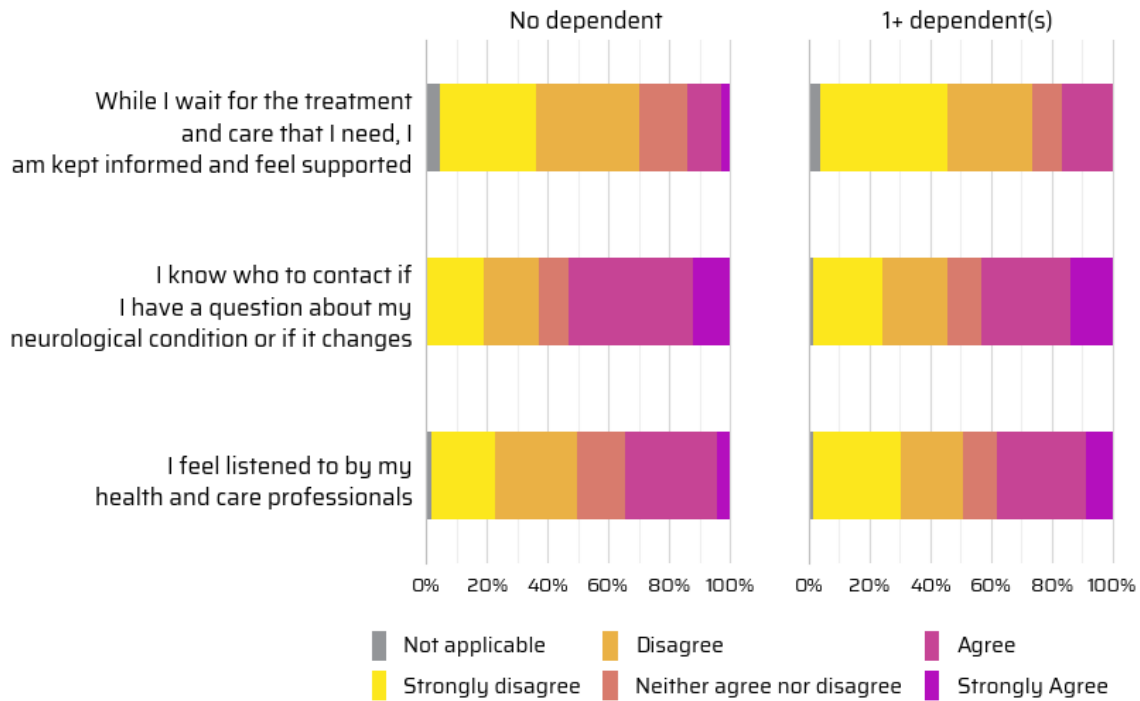


Figure 9 : Experience in health and care among people with vs without dependents.

Table 8 : Experience in health and care among people with vs without dependents.

Number of dependents	Healthcare experience	Response	Respondents	Percentage
1+ dependent(s)	I feel listened to by my health and care professionals	Strongly Agree	7	8.86
		Agree	23	29.11
		Neither agree nor disagree	9	11.39
		Disagree	16	20.25
		Strongly disagree	23	29.11
	I know who to contact if I have a question about my neurological condition or if it changes	Not applicable	1	1.27
		Strongly Agree	11	13.92
		Agree	23	29.11
		Neither agree nor disagree	9	11.39
		Disagree	17	21.52
		Strongly disagree	18	22.78

	Not applicable	1	1.27
	Strongly Agree	0	0.0
	Agree	13	16.46
While I wait for the treatment and care that I need, I am kept informed and feel supported	Neither agree nor disagree	8	10.13
	Disagree	22	27.85
	Strongly disagree	33	41.77
	Not applicable	3	3.8
	Strongly Agree	9	4.41
	Agree	61	29.9
I feel listened to by my health and care professionals	Neither agree nor disagree	33	16.18
	Disagree	55	26.96
	Strongly disagree	43	21.08
	Not applicable	3	1.47
	Strongly Agree	25	12.25
	Agree	83	40.69
I know who to contact if I have a question about my neurological condition or if it changes	Neither agree nor disagree	20	9.8
	Disagree	37	18.14
	Strongly disagree	39	19.12
	Not applicable	0	0.0
	Strongly Agree	6	2.94
	Agree	23	11.27
While I wait for the treatment and care that I need, I am kept informed and feel supported	Neither agree nor disagree	32	15.69
	Disagree	69	33.82
	Strongly disagree	65	31.86
	Not applicable	9	4.41

Access to health and care: extent of mental health needs met.

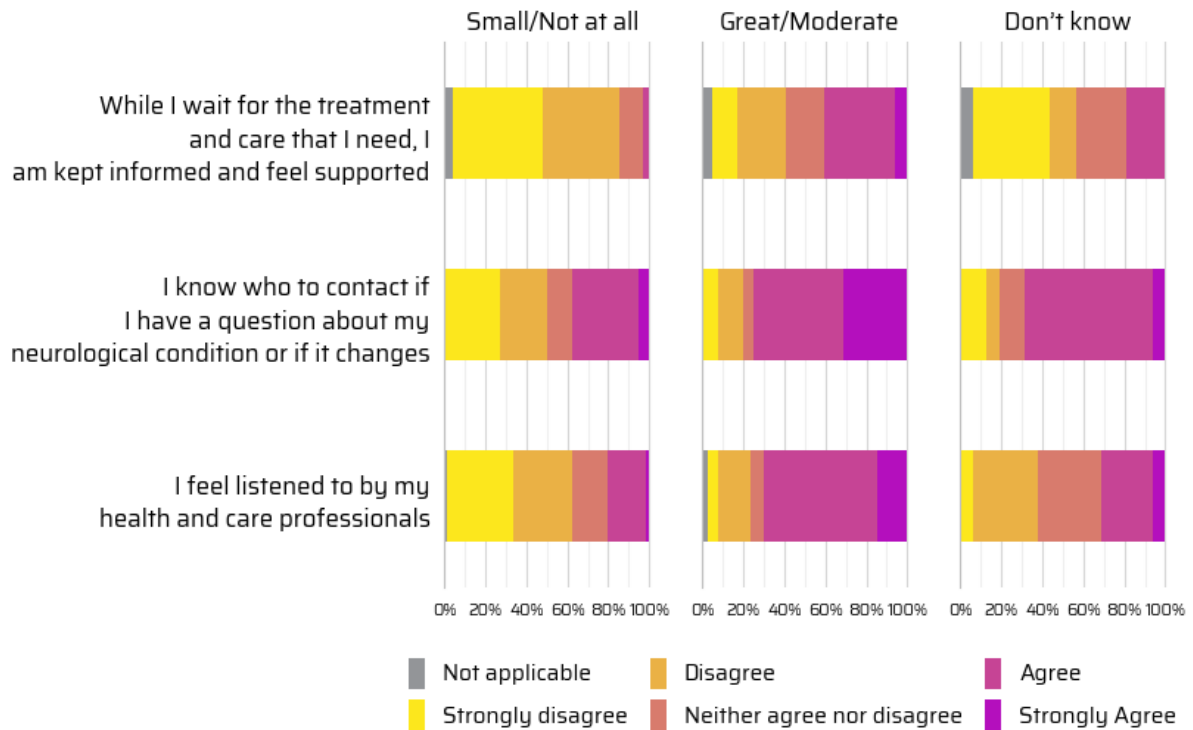


Figure 10 : Experience in health and care among people with different extent of mental health needs met.

Table 9 : Experience in health and care among people with different extent of mental health needs met.

Needs met	Healthcare experience	Response	Respondents	Percentage
Small/Not at all	I feel listened to by my health and care professionals	Strongly Agree	3	1.61
		Agree	35	18.82
		Neither agree nor disagree	32	17.2
		Disagree	53	28.49
		Strongly disagree	61	32.8
	I know who to contact if I have a question about my neurological condition or if it changes	Not applicable	2	1.08
		Strongly Agree	10	5.38
		Agree	60	32.26
		Neither agree nor disagree	23	12.37
		Disagree	43	23.12
		Strongly disagree	49	26.34

		Not applicable	1	0.54
		Strongly Agree	1	0.54
		Agree	5	2.69
	While I wait for the treatment and care that I need, I am kept informed and feel supported	Neither agree nor disagree	21	11.29
		Disagree	70	37.63
		Strongly disagree	82	44.09
		Not applicable	7	3.76
		Strongly Agree	12	14.81
		Agree	45	55.56
	I feel listened to by my health and care professionals	Neither agree nor disagree	5	6.17
		Disagree	13	16.05
		Strongly disagree	4	4.94
		Not applicable	2	2.47
		Strongly Agree	25	30.86
		Agree	36	44.44
Great/Moderate	I know who to contact if I have a question about my neurological condition or if it changes	Neither agree nor disagree	4	4.94
		Disagree	10	12.35
		Strongly disagree	6	7.41
		Not applicable	0	0.0
		Strongly Agree	5	6.17
		Agree	28	34.57
	While I wait for the treatment and care that I need, I am kept informed and feel supported	Neither agree nor disagree	15	18.52
		Disagree	19	23.46
		Strongly disagree	10	12.35
		Not applicable	4	4.94
Don't know		Strongly Agree	1	6.25

	Agree	4	25.0
I feel listened to by my health and care professionals	Neither agree nor disagree	5	31.25
	Disagree	5	31.25
	Strongly disagree	1	6.25
	Not applicable	0	0.0
	Strongly Agree	1	6.25
I know who to contact if I have a question about my neurological condition or if it changes	Agree	10	62.5
	Neither agree nor disagree	2	12.5
	Disagree	1	6.25
	Strongly disagree	2	12.5
	Not applicable	0	0.0
	Strongly Agree	0	0.0
While I wait for the treatment and care that I need, I am kept informed and feel supported	Agree	3	18.75
	Neither agree nor disagree	4	25.0
	Disagree	2	12.5
	Strongly disagree	6	37.5
	Not applicable	1	6.25

Seeing specialists

Purpose of seeing or speaking to a specialist

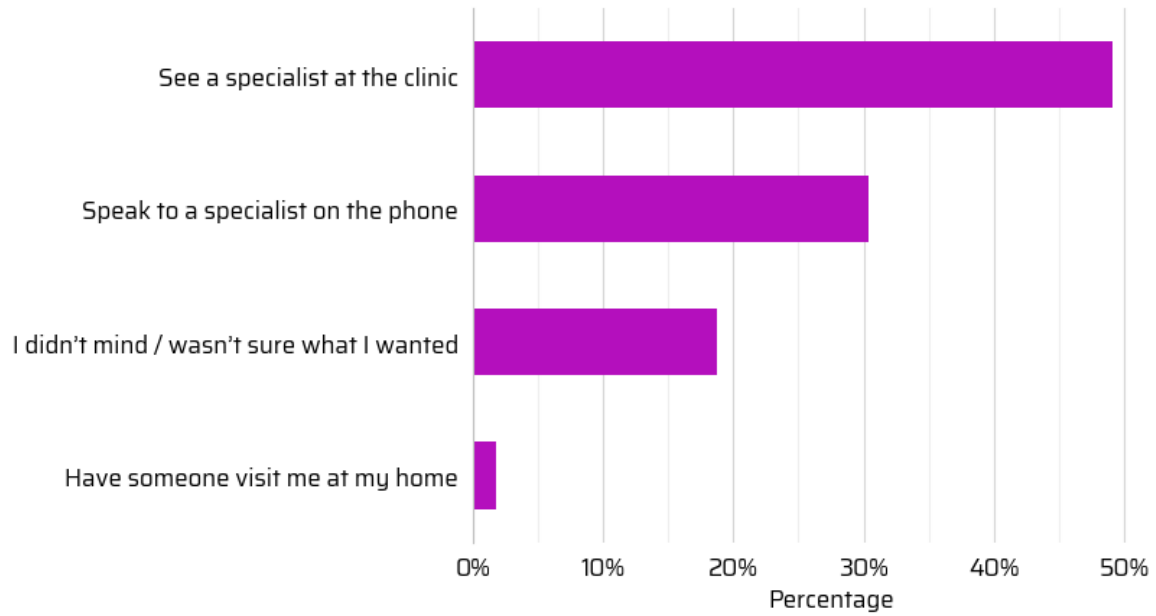


Figure 11 : Purpose of seeing or speaking to a specialist.

Table 10 : Purpose of seeing or speaking to a specialist.

Intention	Respondents	Percentage
See a specialist at the clinic	139	49.12
Speak to a specialist on the phone	86	30.39
I didn't mind / wasn't sure what I wanted	53	18.73
Have someone visit me at my home	5	1.77

Able to meet/speak to a specialist.

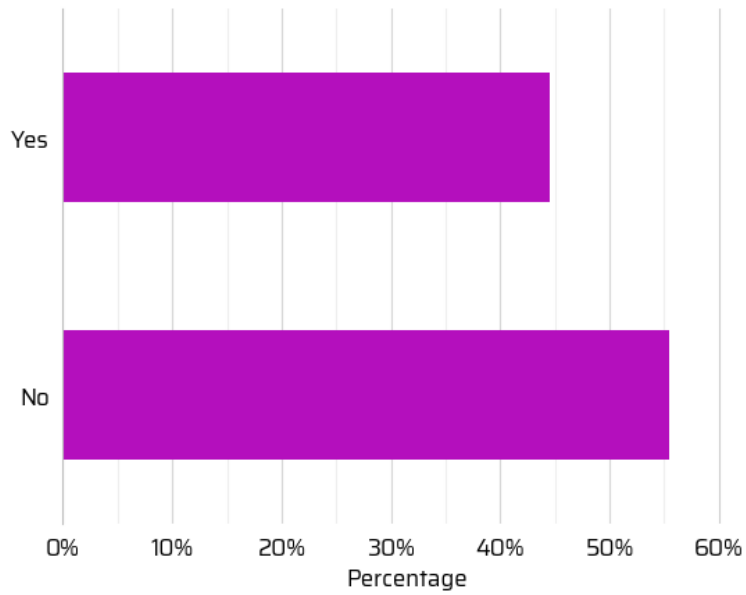


Figure 12 : Whether respondents were able to meet or speak to a specialist.

Table 11 : Whether respondents were able to meet or speak to a specialist.

Appointments	Respondents	Percentage
Yes	126	44.52
No	157	55.48

Convenience of meeting a specialist

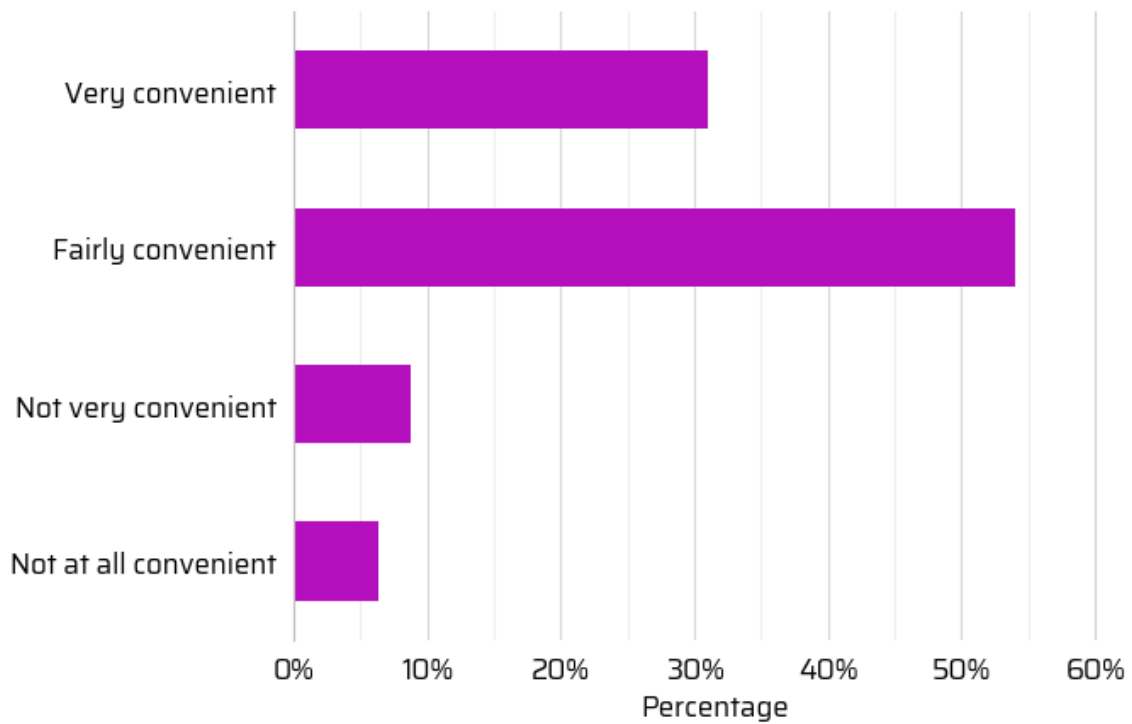


Figure 13 : Convenience of meeting a specialist.

Table 12 : Convenience of meeting a specialist.

Convenience	Respondents	Percentage
Very convenient	39	30.95
Fairly convenient	68	53.97
Not very convenient	11	8.73
Not at all convenient	8	6.35

Reasons of not getting an appointment or a convenient one

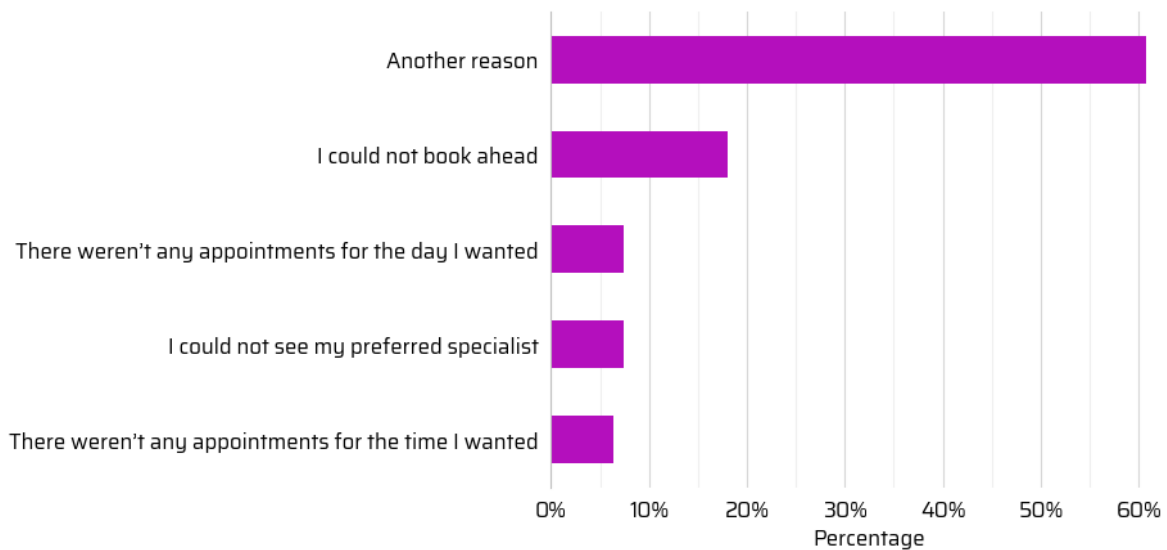


Figure 14 : Reasons of not getting an appointment or a convenient one.

Table 13 : Reasons of not getting an appointment or a convenient one.

Reason	Respondents	Percentage
Another reason	172	60.78
I could not book ahead	51	18.02
I could not see my preferred specialist	21	7.42
There weren't any appointments for the day I wanted	21	7.42
There weren't any appointments for the time I wanted	18	6.36

Qualitative analysis

Reasons of not getting an appointment or a convenient one:

This question was asked apart from the options given for the reasons of not getting an appointment. The reasons (some with examples) are listed below:

1. Cancellation

"I had two appointments cancelled"

2. Told not needed (e.g., by the GP) or considered unnecessary

"Not considered necessary by the consultant."

3. No specialist available

Brain & Spine Foundation registered charity no. 1098528

“Lack of specialist with appropriate experience”

4. Removed from the list

“I was discharged from the consultants list over the phone”

5. Still waiting for an appointment or received no response

“I’ve been told I’m on a long waiting list and must wait until I receive a letter telling me that I am able to book the appointment which I should have had four months ago.”

“Lack of staff available, unable to contact a human being, required to leave answerphone messages not knowing when calls will be returned.”

6. Journey is too long or too difficult to get to the appointment

“Had to travel quite a distance to see them.”

7. Patient initiated follow-up (PIFU)

“Last year was put on the PIFU scheme. This is not ideal and just delays getting a follow up appointment.”

8. Need to attend another appointment

“I had another hospital appointment and the clinic I was in was running an hour late so had to leave to be on time for a different hospital as they were running over an hour late.”

9. Not seen as beneficial

“I Stopped bothering to see a specialist as there didn’t seem anything that they could help me with as for physio.”

“Haven’t seen a Neuro specialist for years last time it was pointless they just didn’t know what to do with me and my symptoms.”

10. Too complicated to make an appointment

“It’s too complicated to see a specialist through the nhs. Had to do it privately. I have never seen or spoken to anyone since I left hospital in october 2020”

“I don’t know how to make an appointment with a specialist. I always have to try to get a gp appointment and I find they don’t understand my condition or what I need.”

11. Not told to get one/not offered one

Brain & Spine Foundation registered charity no. 1098528

“I wasn’t offered any options.”

12. No appointment available

“I was told there weren’t any appointments available.”

13. Admin error

“Communication breakdown between health and administration staff-request brain scan not picked up by agency neurologist or GP with nobody taking responsibility.”

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

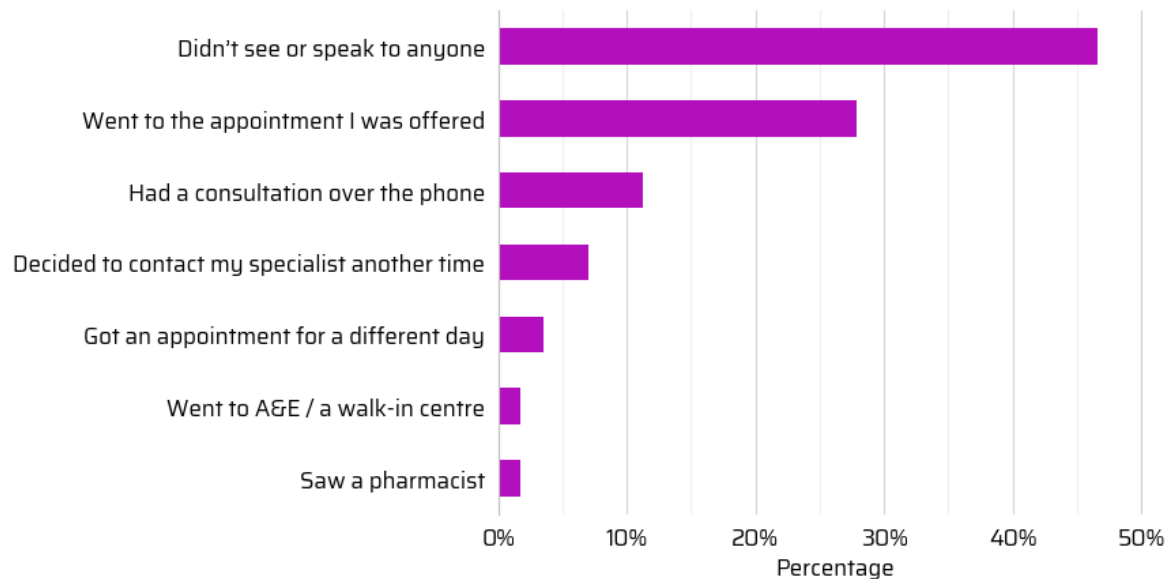


Figure 15 : Action taken following not getting an appointment/not offered a convenient one.

Table 14 : Action taken following not getting an appointment/not offered a convenient one.

Action	Respondents	Percentage
Didn't see or speak to anyone	132	46.64
Went to the appointment I was offered	79	27.92
Had a consultation over the phone	32	11.31
Decided to contact my specialist another time	20	7.07
Got an appointment for a different day	10	3.53
Saw a pharmacist	5	1.77
Went to A&E / a walk-in centre	5	1.77

Medical appointments

Access to medical appointments in the last eight weeks

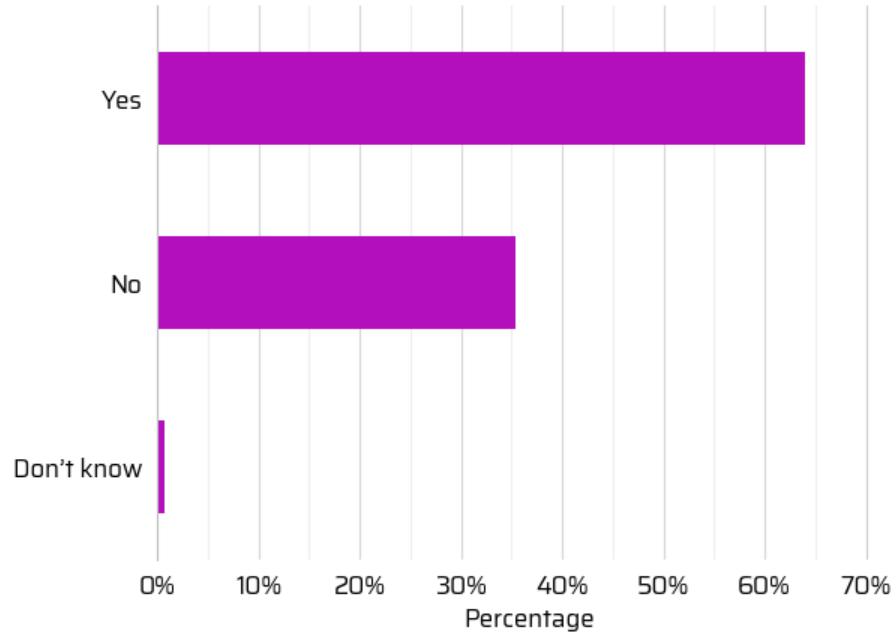


Figure 16 : Access to medical appointments in the last eight weeks.

Table 15 : Access to medical appointments in the last eight weeks.

Appointments	Respondents	Percentage
Yes	181	63.96
No	100	35.34
Don't know	2	0.71

Number of medical appointments

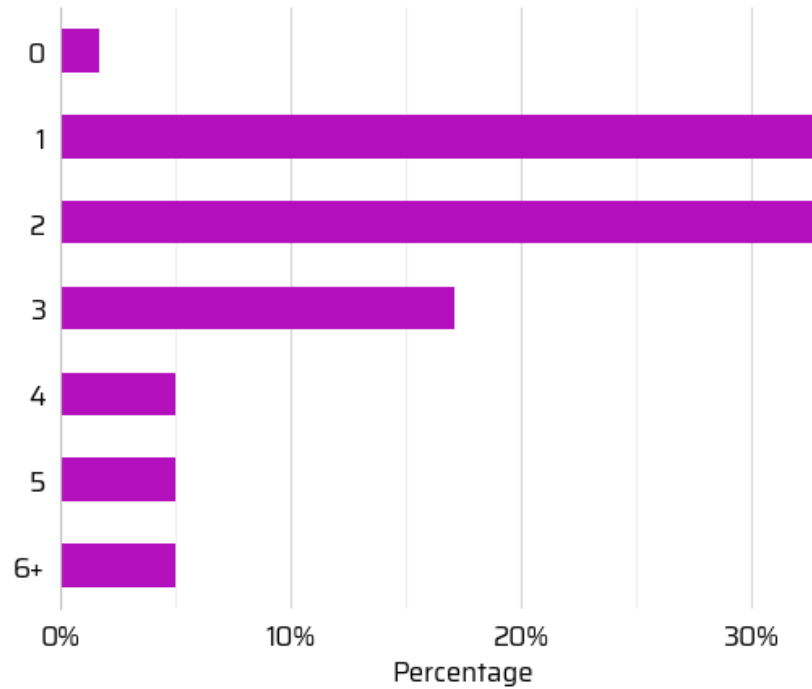


Figure 17 : Number of medical appointments.

Table 16 : Number of medical appointments.

Number of appointments	Respondents	Percentage
0	3	1.66
1	60	33.15
2	60	33.15
3	31	17.13
4	9	4.97
5	9	4.97
6+	9	4.97

Helpfulness of medical appointments

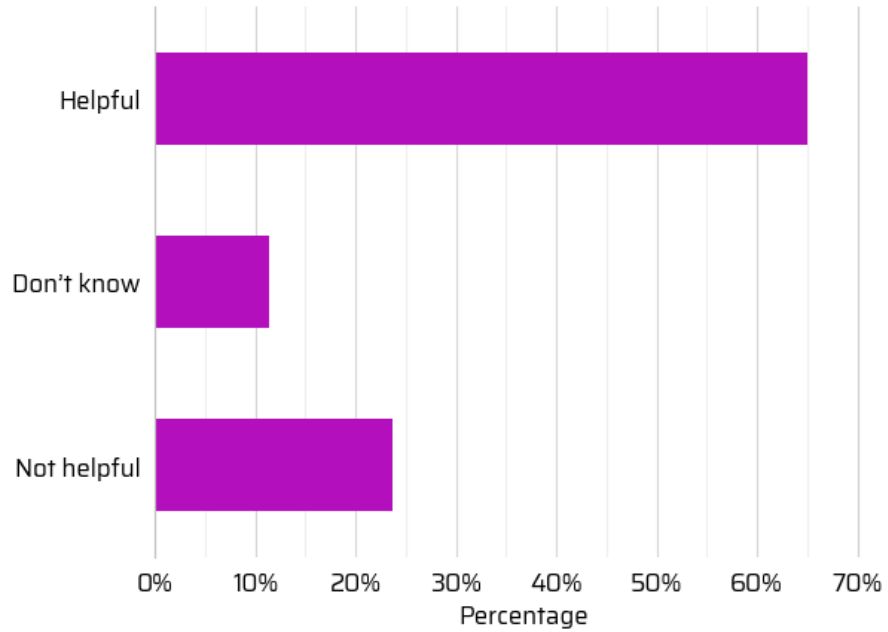


Figure 18 : Helpfulness of medical appointments held in the last eight weeks.

Table 17 : Helpfulness of medical appointments held in the last eight weeks.

Helpfulness	Respondents	Percentage
Helpful	184	65.02
Don't know	32	11.31
Not helpful	67	23.67

Specialty of medical appointments

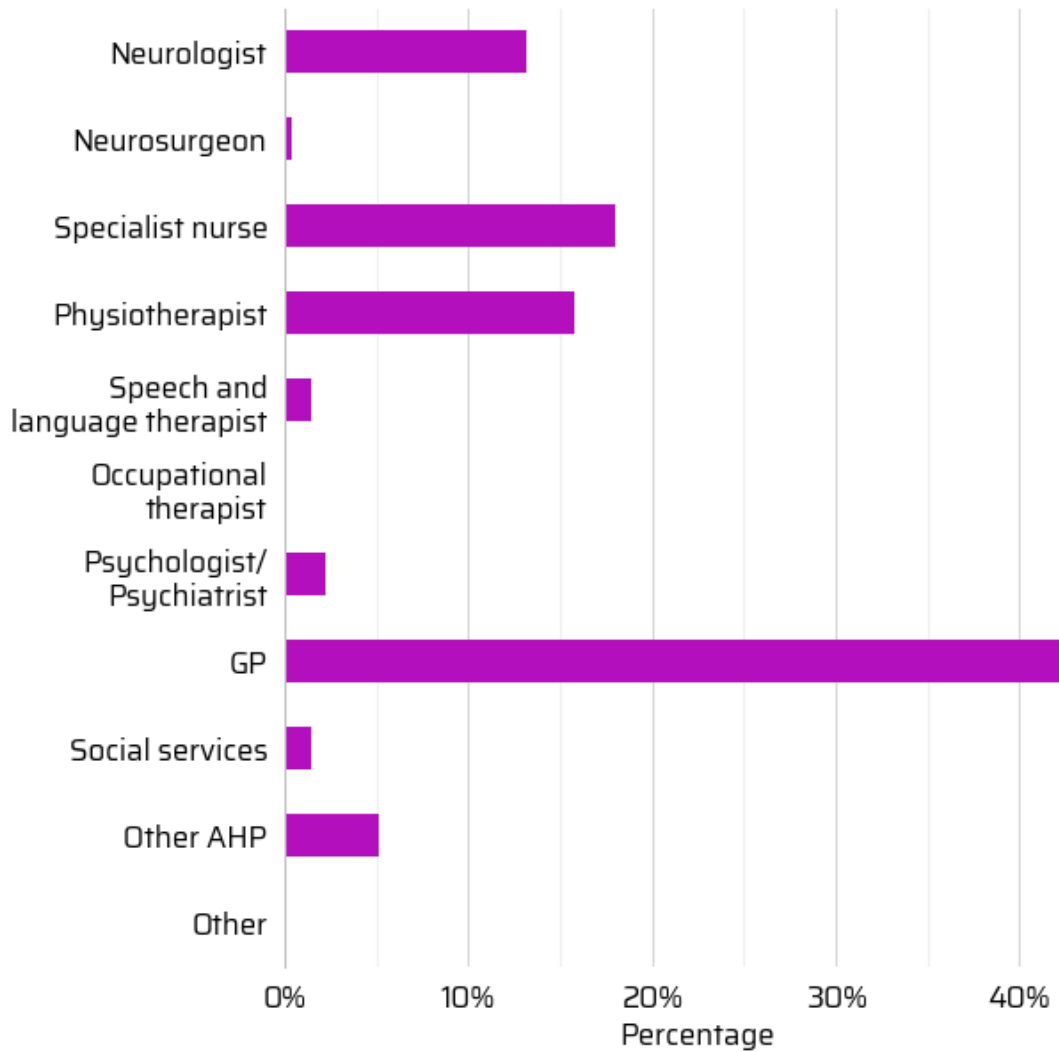


Figure 19 : Speciality of the medical appointments held in the last eight weeks.

Table 18 : Speciality of the medical appointments held in the last eight weeks.

Specialty	Respondents	Percentage
Neurologist	36	13.19
Neurosurgeon	1	0.37
Specialist nurse	49	17.95
Physiotherapist	43	15.75
Speech and language therapist	4	1.47
Occupational therapist	0	0.0

Psychologist/Psychiatrist	6	2.2
GP	116	42.49
Social services	4	1.47
Other AHP	14	5.13
Other	0	0.0

Mode of medical appointments completed.

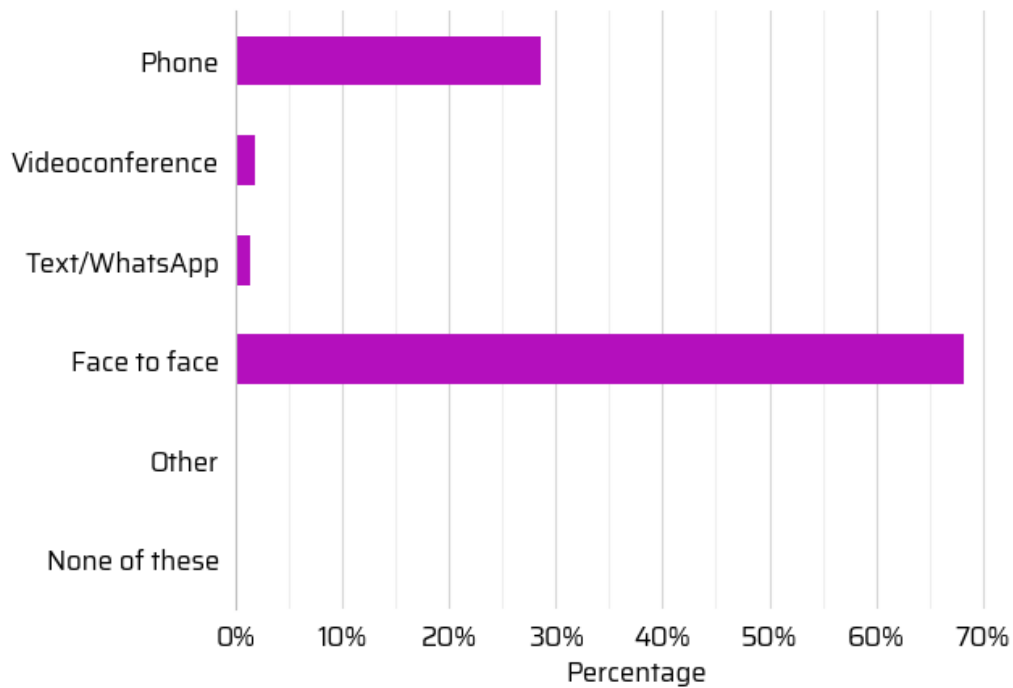


Figure 20 : Mode of medical appointments completed in the last eight weeks.

Table 19 : Mode of medical appointments completed in the last eight weeks.

Mode	Respondents	Percentage
Phone	81	28.62
Videoconference	5	1.77
Text/WhatsApp	4	1.41
Face to face	193	68.2
Other	0	0.0
None of these	0	0.0

Mental health

Current feelings

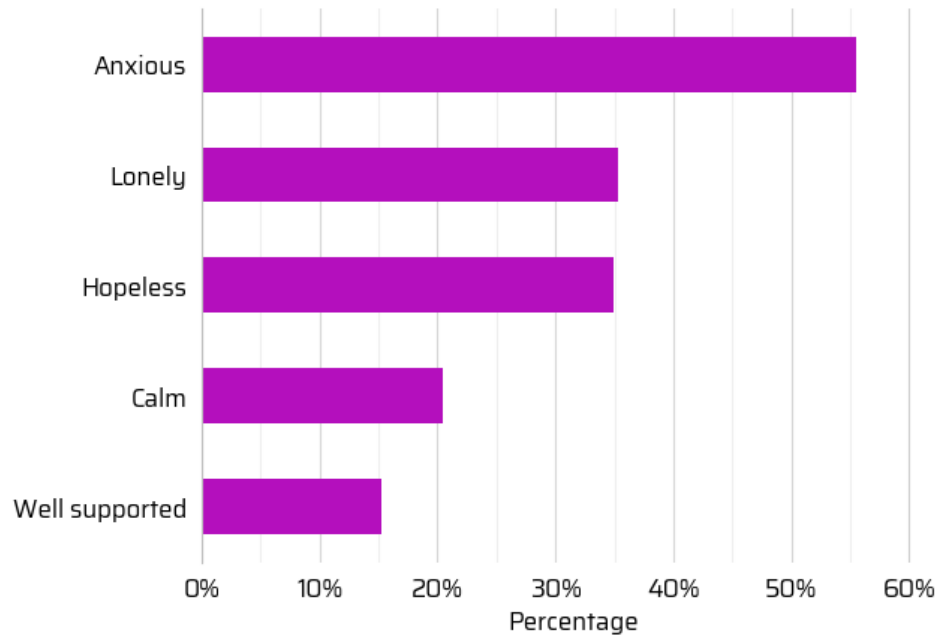


Figure 21 : Feelings of the respondents at the time of the survey.

Table 20 : Feelings of the respondents at the time of the survey.

Feelings	Count	Percentage
Well supported	43	15.19
Calm	58	20.49
Hopeless	99	34.98
Lonely	100	35.34
Anxious	157	55.48

Extent mental health needs are met.

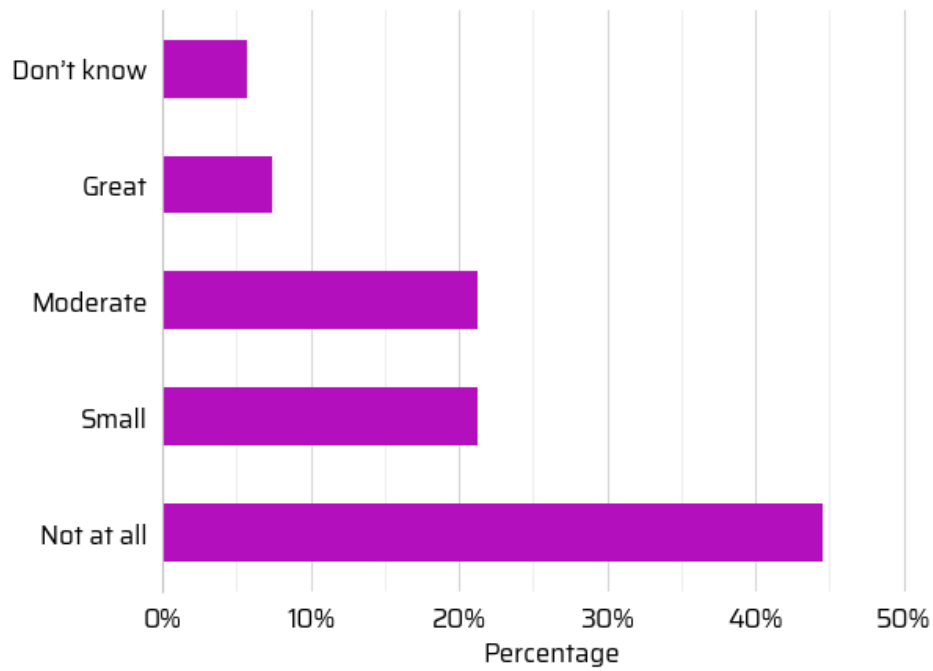


Figure 22 : Extent respondents reported their mental health needs were being met.

Table 21 : Extent respondents reported their mental health needs were being met.

Needs met	Respondents	Percentage
Don't know	16	5.65
Great	21	7.42
Moderate	60	21.2
Small	60	21.2
Not at all	126	44.52

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

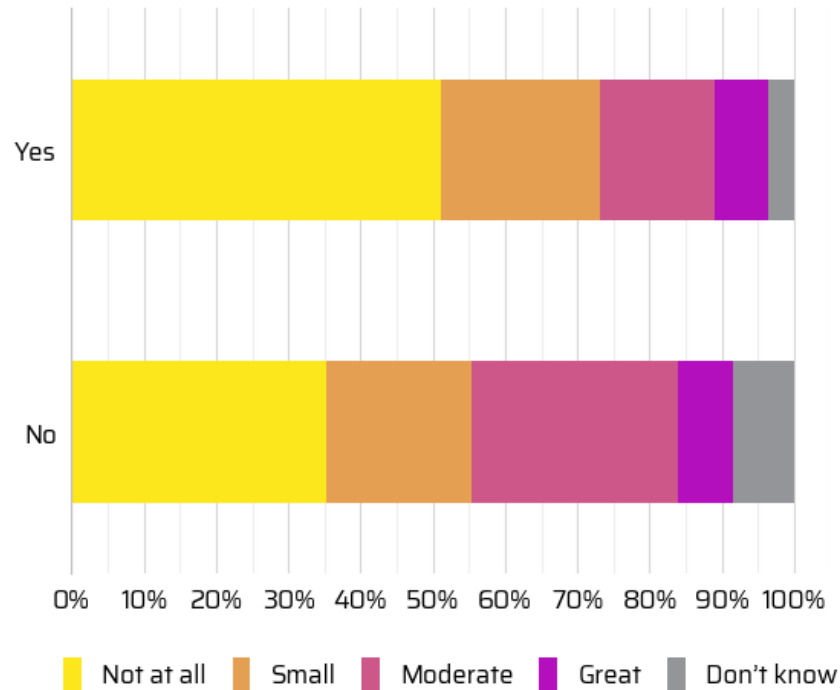


Figure 23 : Extent respondents reported their mental health needs were being met, broken down by whether diagnosed with multiple neurological conditions.

Table 22 : 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	6	3.66
	Great	12	7.32
	Moderate	26	15.85
	Small	36	21.95
	Not at all	84	51.22
No	Don't know	10	8.4
	Great	9	7.56
	Moderate	34	28.57
	Small	24	20.17
	Not at all	42	35.29

Extent mental health needs are met by age groups.

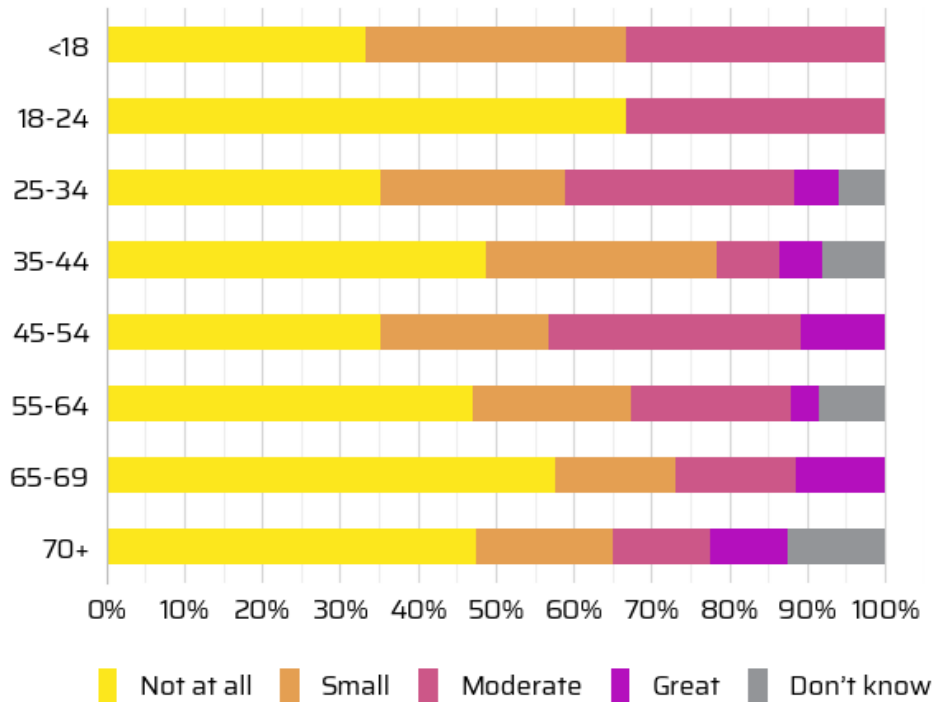


Figure 24 : Extent respondents reported their mental health needs were being met, broken down by age group.

Table 23 : Extent respondents reported their mental health needs were being met, broken down by age group.

Age	Needs met	Respondents	Percentage
<18	Don't know	0	0.0
	Great	0	0.0
	Moderate	1	33.33
	Small	1	33.33
	Not at all	1	33.33
18-24	Don't know	0	0.0
	Great	0	0.0
	Moderate	1	33.33
	Small	0	0.0
	Not at all	2	66.67

	Don't know	1	5.88
	Great	1	5.88
25-34	Moderate	5	29.41
	Small	4	23.53
	Not at all	6	35.29
	Don't know	3	8.11
	Great	2	5.41
35-44	Moderate	3	8.11
	Small	11	29.73
	Not at all	18	48.65
	Don't know	0	0.0
	Great	8	10.81
45-54	Moderate	24	32.43
	Small	16	21.62
	Not at all	26	35.14
	Don't know	7	8.43
	Great	3	3.61
55-64	Moderate	17	20.48
	Small	17	20.48
	Not at all	39	46.99
	Don't know	0	0.0
	Great	3	11.54
65-69	Moderate	4	15.38
	Small	4	15.38
	Not at all	15	57.69
	Don't know	5	12.5
70+	Great	4	10.0

Moderate	5	12.5
Small	7	17.5
Not at all	19	47.5

Extent mental health needs are met by gender.

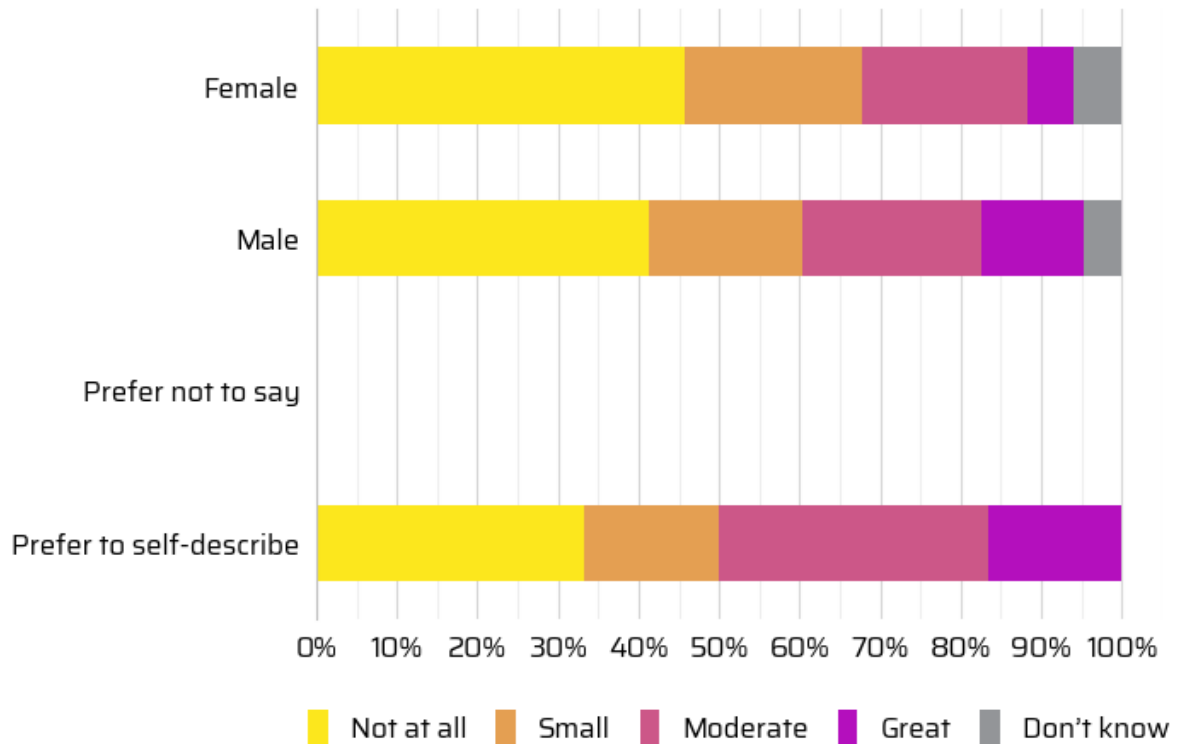


Figure 25 : Extent respondents reported their mental health needs were being met, broken down by gender.

Table 24 : Extent respondents reported their mental health needs were being met, broken down by gender.

Gender	Needs met	Respondents	Percentage
Female	Don't know	13	6.07
	Great	12	5.61
	Moderate	44	20.56
	Small	47	21.96
	Not at all	98	45.79
Male	Don't know	3	4.76

	Great	8	12.7
	Moderate	14	22.22
	Small	12	19.05
	Not at all	26	41.27
	Don't know	0	0.0
Prefer not to say	Great	0	0.0
	Moderate	0	0.0
	Small	0	0.0
	Not at all	0	0.0
	Don't know	0	0.0
Prefer to self-describe	Great	1	16.67
	Moderate	2	33.33
	Small	1	16.67
	Not at all	2	33.33
	Don't know	0	0.0

Extent mental health needs are met by employment status.

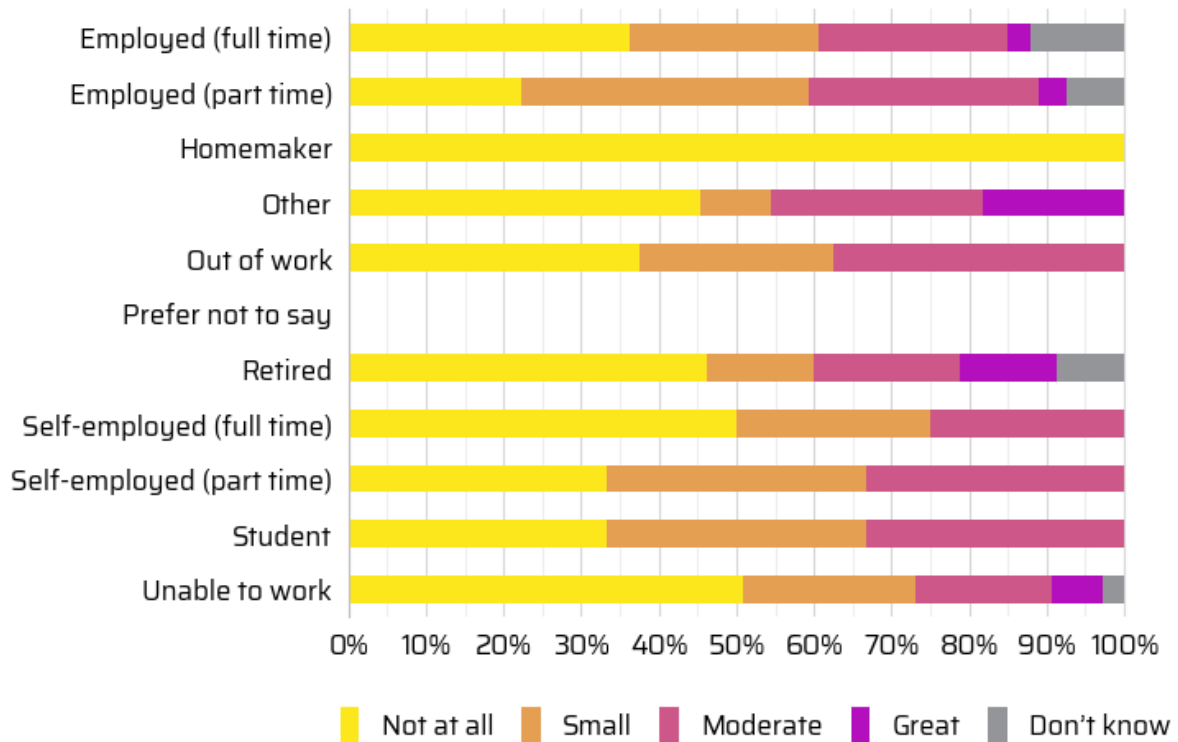


Figure 26 : Extent respondents reported their mental health needs were being met, broken down by employment status.

Table 25 : 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	4	12.12
	Great	1	3.03
	Moderate	8	24.24
	Small	8	24.24
	Not at all	12	36.36
Employed (part time)	Don't know	2	7.41
	Great	1	3.7
	Moderate	8	29.63
	Small	10	37.04
	Not at all	6	22.22

Homemaker	Don't know	0	0.0
	Great	0	0.0
	Moderate	0	0.0
	Small	0	0.0
	Not at all	3	100.0
Other	Don't know	0	0.0
	Great	2	18.18
	Moderate	3	27.27
	Small	1	9.09
	Not at all	5	45.45
Out of work	Don't know	0	0.0
	Great	0	0.0
	Moderate	3	37.5
	Small	2	25.0
	Not at all	3	37.5
Prefer not to say	Don't know	0	0.0
	Great	0	0.0
	Moderate	0	0.0
	Small	0	0.0
	Not at all	0	0.0
Retired	Don't know	7	8.75
	Great	10	12.5
	Moderate	15	18.75
	Small	11	13.75
	Not at all	37	46.25
Self-employed (full time)	Don't know	0	0.0
	Great	0	0.0
	Moderate	1	25.0

	Small	1	25.0
	Not at all	2	50.0
	Don't know	0	0.0
	Great	0	0.0
Self-employed (part time)	Moderate	2	33.33
	Small	2	33.33
	Not at all	2	33.33
	Don't know	0	0.0
	Great	0	0.0
Student	Moderate	1	33.33
	Small	1	33.33
	Not at all	1	33.33
	Don't know	3	2.78
	Great	7	6.48
Unable to work	Moderate	19	17.59
	Small	24	22.22
	Not at all	55	50.93

Extent mental health needs are met by number of dependents.

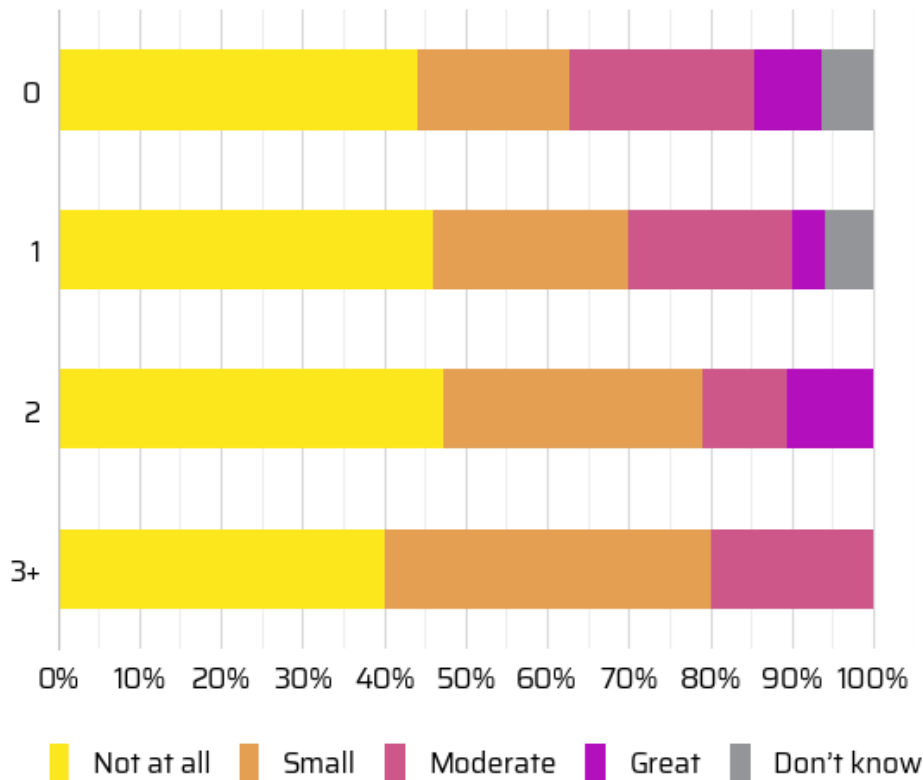


Figure 27 : Extent respondents reported their mental health needs were being met, broken down by number of dependents.

Table 26 : 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	13	6.37
	Great	17	8.33
	Moderate	46	22.55
	Small	38	18.63
	Not at all	90	44.12
1	Don't know	3	6.0
	Great	2	4.0
	Moderate	10	20.0
	Small	12	24.0

	Not at all	23	46.0
	Don't know	0	0.0
	Great	2	10.53
2	Moderate	2	10.53
	Small	6	31.58
	Not at all	9	47.37
	Don't know	0	0.0
	Great	0	0.0
3+	Moderate	2	20.0
	Small	4	40.0
	Not at all	4	40.0

Frequency NHS A&E/emergency services were sought

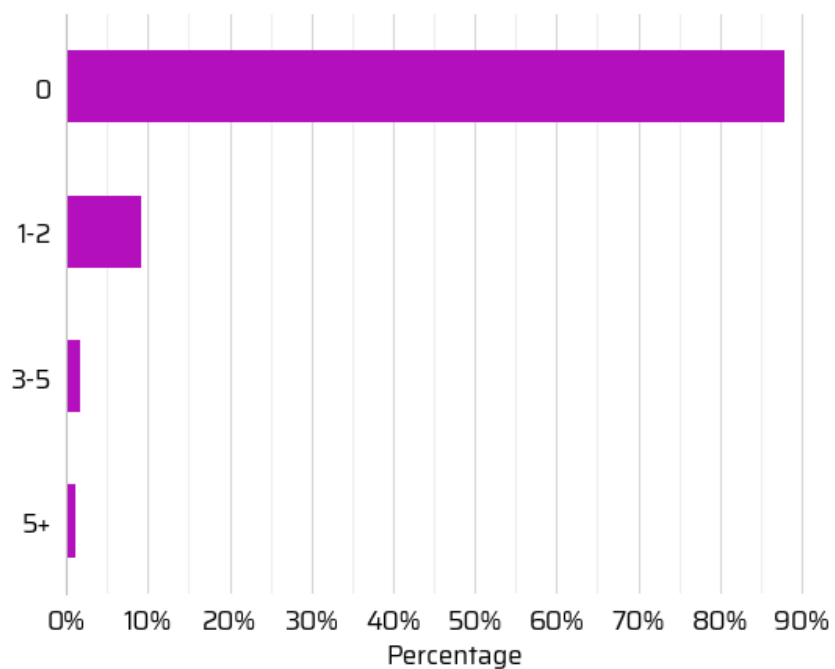


Figure 28 : Frequency that NHS A&E/emergency services were sought in the last eight weeks.

Table 27 : Frequency that NHS A&E/emergency services were sought in the last eight weeks.

Frequency	Respondents	Percentage
0	249	87.99
1-2	26	9.19
3-5	5	1.77
5+	3	1.06

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

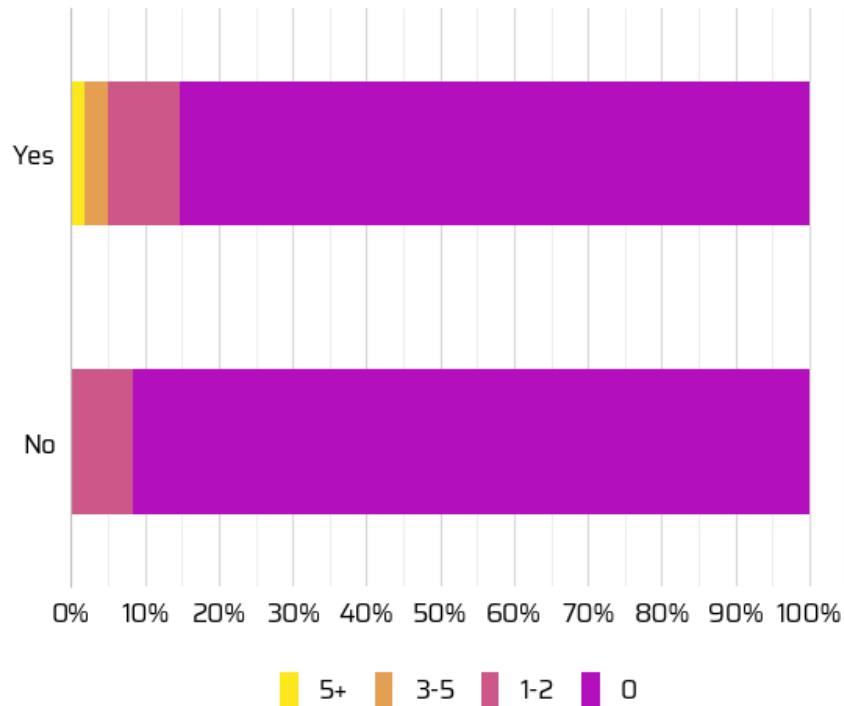


Figure 29 : Frequency that NHS A&E/emergency services were sought, broken down by whether diagnosed with multiple neurological conditions.

Table 28 : 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	140	85.37
	1-2	16	9.76
	3-5	5	3.05

	5+	3	1.83
	0	109	91.6
No	1-2	10	8.4
	3-5	0	0.0
	5+	0	0.0

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

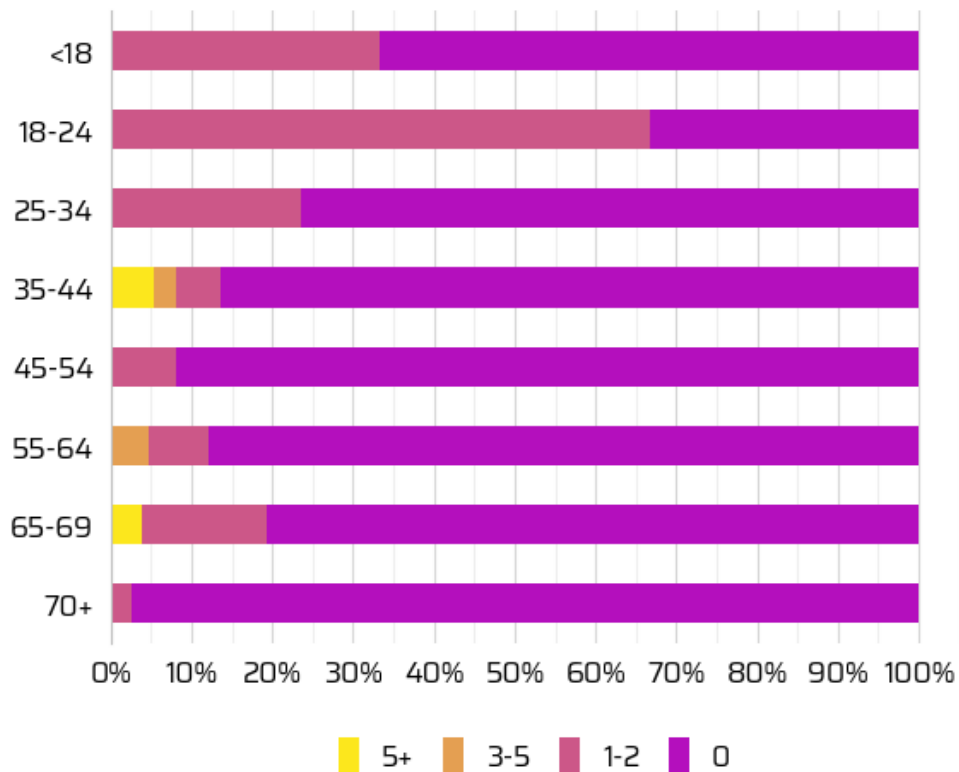


Figure 30 : Frequency that NHS A&E/emergency services were sought, broken down by age group.

Table 29 : Frequency that NHS A&E/emergency services were sought, broken down by age group.

Age	Frequency	Respondents	Percentage
<18	0	2	66.67
	1-2	1	33.33
	3-5	0	0.0
	5+	0	0.0
18-24	0	1	33.33

	1-2	2	66.67
	3-5	0	0.0
	5+	0	0.0
	0	13	76.47
25-34	1-2	4	23.53
	3-5	0	0.0
	5+	0	0.0
	0	32	86.49
35-44	1-2	2	5.41
	3-5	1	2.7
	5+	2	5.41
	0	68	91.89
45-54	1-2	6	8.11
	3-5	0	0.0
	5+	0	0.0
	0	73	87.95
55-64	1-2	6	7.23
	3-5	4	4.82
	5+	0	0.0
	0	21	80.77
65-69	1-2	4	15.38
	3-5	0	0.0
	5+	1	3.85
	0	39	97.5
70+	1-2	1	2.5
	3-5	0	0.0
	5+	0	0.0

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

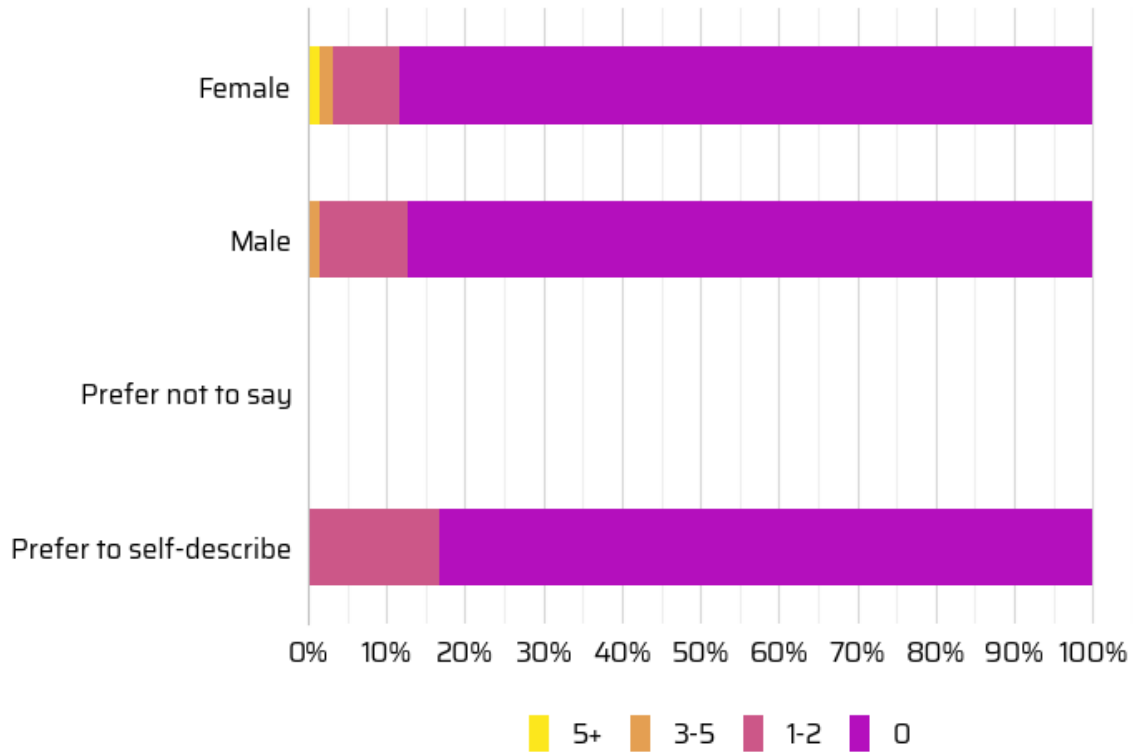


Figure 31 : Frequency that NHS A&E/emergency services were sought, broken down by gender.

Table 30 : Frequency that NHS A&E/emergency services were sought, broken down by gender.

Gender	Frequency	Respondents	Percentage
Female	0	189	88.32
	1-2	18	8.41
	3-5	4	1.87
	5+	3	1.4
Male	0	55	87.3
	1-2	7	11.11
	3-5	1	1.59
	5+	0	0.0
Prefer not to say	0	0	0.0
	1-2	0	0.0
	3-5	0	0.0

	5+	0	0.0
	0	5	83.33
Prefer to self-describe	1-2	1	16.67
	3-5	0	0.0
	5+	0	0.0

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

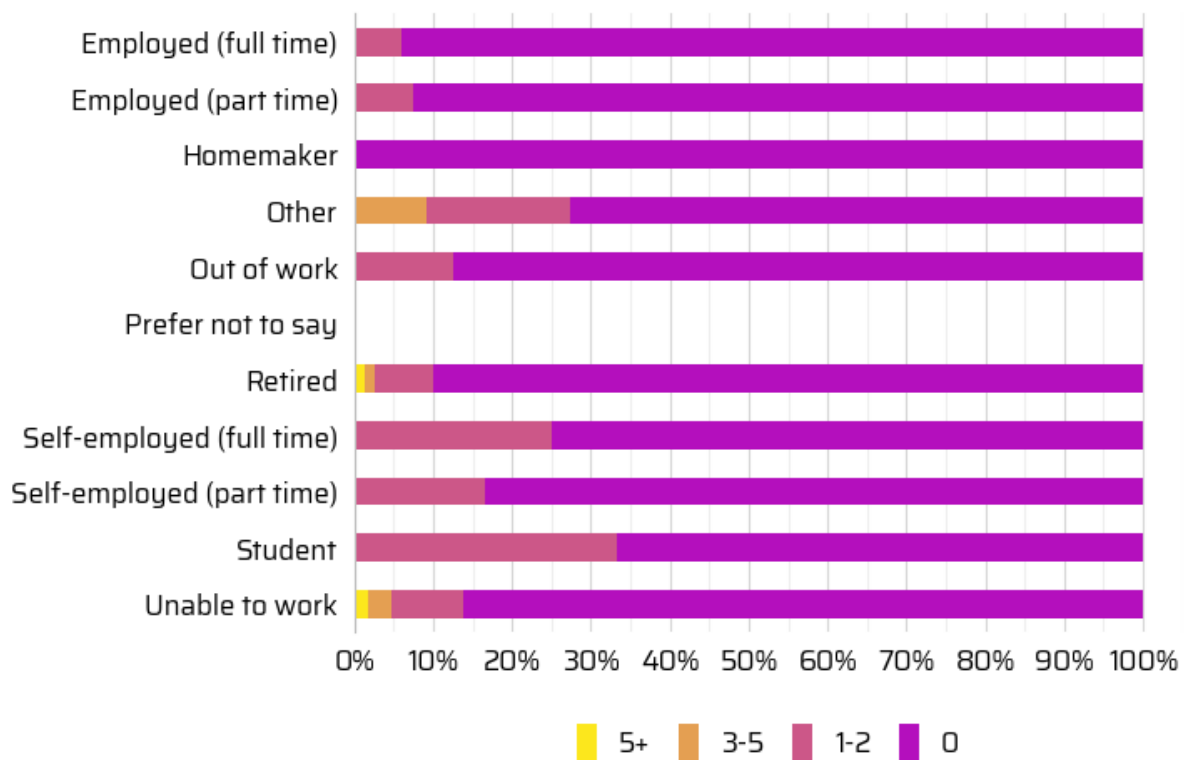


Figure 32 : Frequency that NHS A&E/emergency services were sought, broken down by employment status.

Table 31 : Frequency that NHS A&E/emergency services were sought, broken down by employment status.

Employment status	Frequency	Respondents	Percentage
Employed (full time)	0	31	93.94
	1-2	2	6.06
	3-5	0	0.0

	5+	0	0.0
	0	25	92.59
Employed (part time)	1-2	2	7.41
	3-5	0	0.0
	5+	0	0.0
	0	3	100.0
Homemaker	1-2	0	0.0
	3-5	0	0.0
	5+	0	0.0
	0	8	72.73
Other	1-2	2	18.18
	3-5	1	9.09
	5+	0	0.0
	0	7	87.5
Out of work	1-2	1	12.5
	3-5	0	0.0
	5+	0	0.0
	0	0	0.0
Prefer not to say	1-2	0	0.0
	3-5	0	0.0
	5+	0	0.0
	0	72	90.0
Retired	1-2	6	7.5
	3-5	1	1.25
	5+	1	1.25
	0	3	75.0
Self-employed (full time)	1-2	1	25.0
	3-5	0	0.0

	5+	0	0.0
	0	5	83.33
Self-employed (part time)	1-2	1	16.67
	3-5	0	0.0
	5+	0	0.0
	0	2	66.67
Student	1-2	1	33.33
	3-5	0	0.0
	5+	0	0.0
	0	93	86.11
Unable to work	1-2	10	9.26
	3-5	3	2.78
	5+	2	1.85
	0		

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

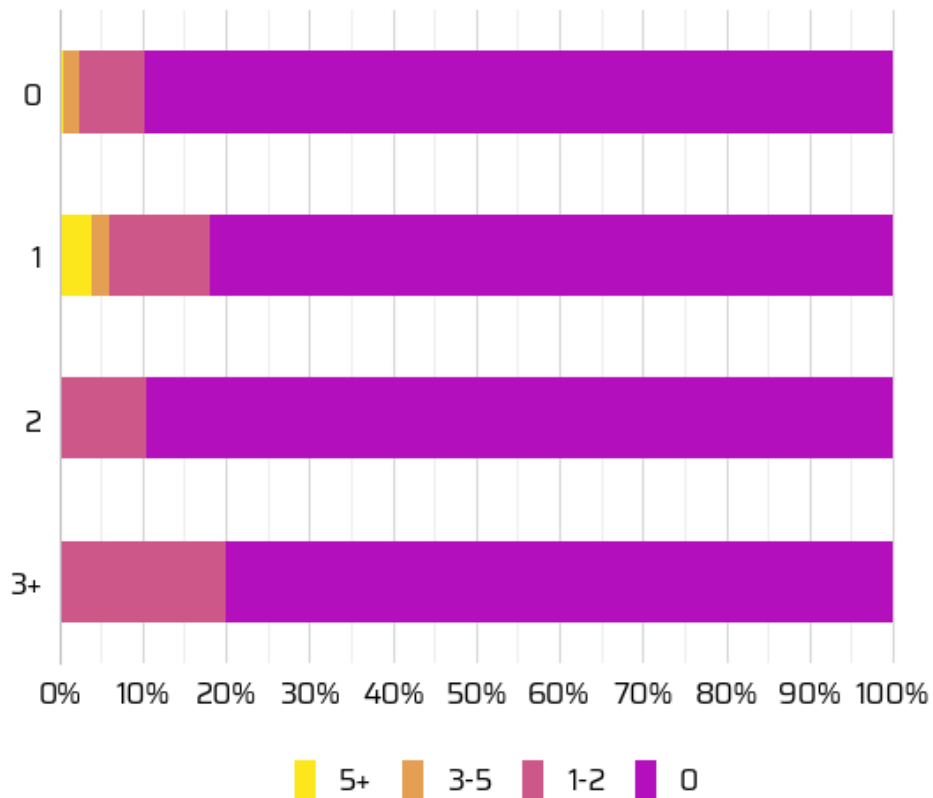


Figure 33 : Frequency that NHS A&E/emergency services were sought, broken down by number of dependents.

Table 32 : Frequency that NHS A&E/emergency services were sought, broken down by number of dependents.

Number of dependents	Frequency	Respondents	Percentage
0	0	183	89.71
	1-2	16	7.84
	3-5	4	1.96
	5+	1	0.49
1	0	41	82.0
	1-2	6	12.0
	3-5	1	2.0
	5+	2	4.0

2	0	17	89.47
	1-2	2	10.53
	3-5	0	0.0
	5+	0	0.0
3+	0	8	80.0
	1-2	2	20.0
	3-5	0	0.0
	5+	0	0.0

Overall experience of health & care

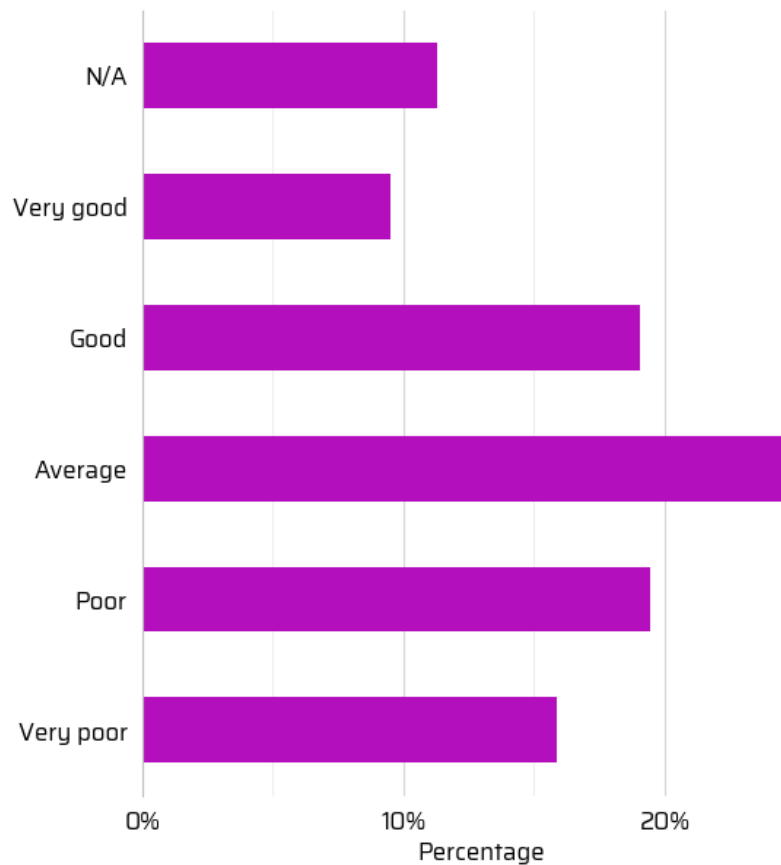


Figure 34 : Overall experience of healthcare.

Table 33 : Overall experience of healthcare.

Experience	Respondents	Percentage
N/A	32	11.31
Very good	27	9.54

Brain & Spine Foundation registered charity no. 1098528

Good	54	19.08
Average	70	24.73
Poor	55	19.43
Very poor	45	15.9

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

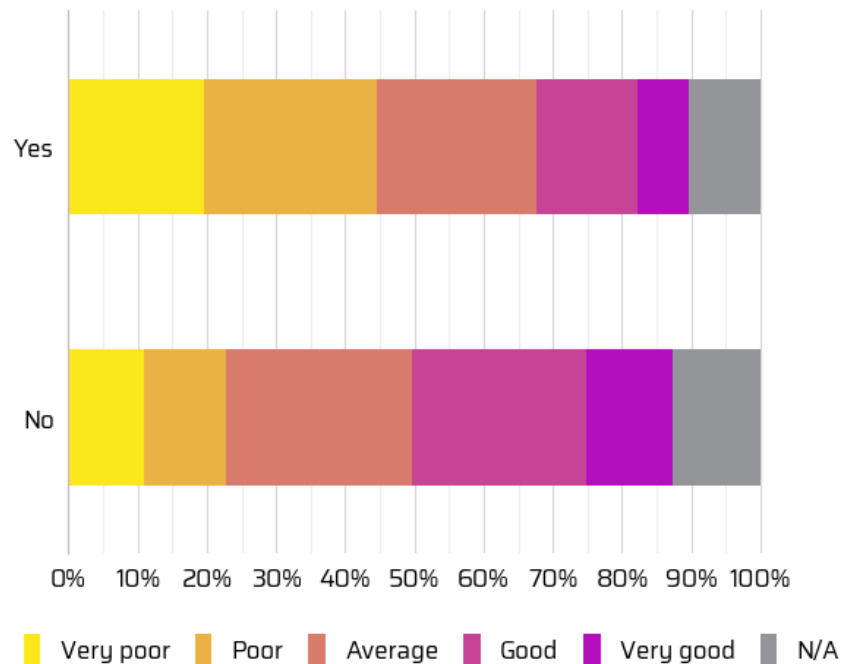


Figure 35 : Overall experience of healthcare, broken down by whether diagnosed with multiple neurological conditions.

Table 34: Overall experience of healthcare, broken down by whether diagnosed with multiple neurological conditions.

Multiple neurological conditions	Experience	Respondents	Percentage
Yes	N/A	17	10.37
	Very good	12	7.32
	Good	24	14.63
	Average	38	23.17
	Poor	41	25.0

	Very poor	32	19.51
	N/A	15	12.61
	Very good	15	12.61
No	Good	30	25.21
	Average	32	26.89
	Poor	14	11.76
	Very poor	13	10.92

Overall experience of health & care by age group.

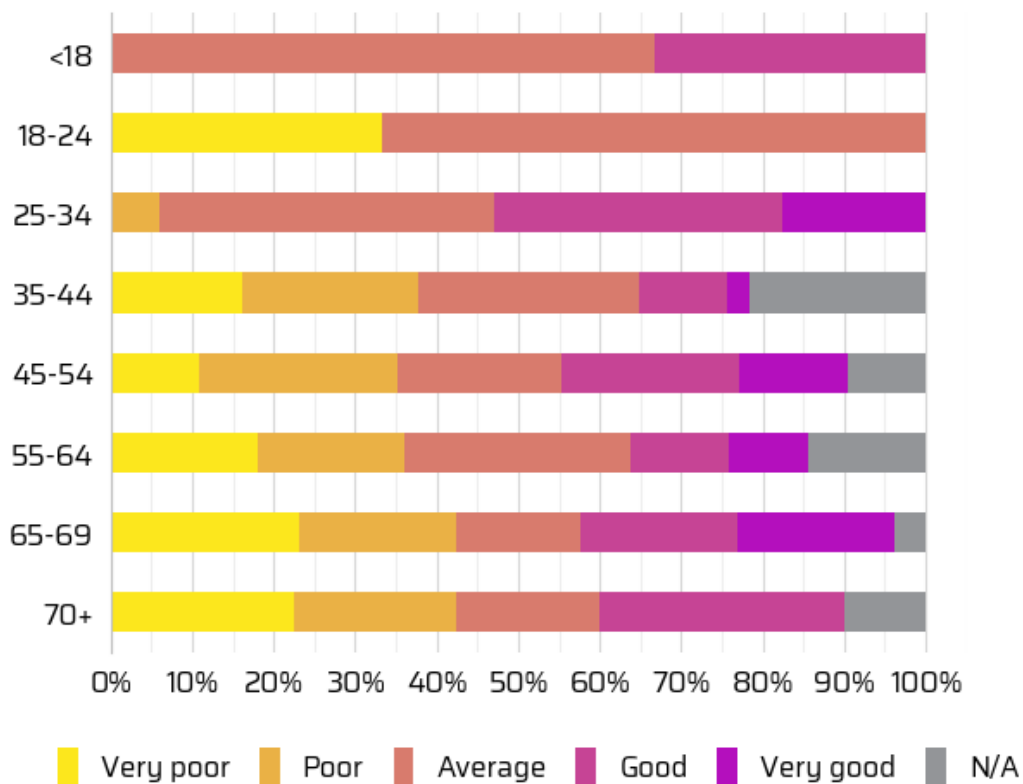


Figure 36 : Overall experience of healthcare, broken down by age group.

Table 35 : Overall experience of healthcare, broken down by age group.

Age	Experience	Respondents	Percentage
	N/A	0	0.0
<18	Very good	0	0.0
	Good	1	33.33

Brain & Spine Foundation registered charity no. 1098528

	Average	2	66.67
	Poor	0	0.0
	Very poor	0	0.0
	N/A	0	0.0
	Very good	0	0.0
	Good	0	0.0
18-24	Average	2	66.67
	Poor	0	0.0
	Very poor	1	33.33
	N/A	0	0.0
	Very good	3	17.65
	Good	6	35.29
25-34	Average	7	41.18
	Poor	1	5.88
	Very poor	0	0.0
	N/A	8	21.62
	Very good	1	2.7
	Good	4	10.81
35-44	Average	10	27.03
	Poor	8	21.62
	Very poor	6	16.22
	N/A	7	9.46
	Very good	10	13.51
	Good	16	21.62
45-54	Average	15	20.27
	Poor	18	24.32
	Very poor	8	10.81
55-64	N/A	12	14.46

	Very good	8	9.64
	Good	10	12.05
	Average	23	27.71
	Poor	15	18.07
	Very poor	15	18.07
	N/A	1	3.85
65-69	Very good	5	19.23
	Good	5	19.23
	Average	4	15.38
	Poor	5	19.23
	Very poor	6	23.08
	N/A	4	10.0
70+	Very good	0	0.0
	Good	12	30.0
	Average	7	17.5
	Poor	8	20.0
	Very poor	9	22.5

Overall experience of health & care by gender

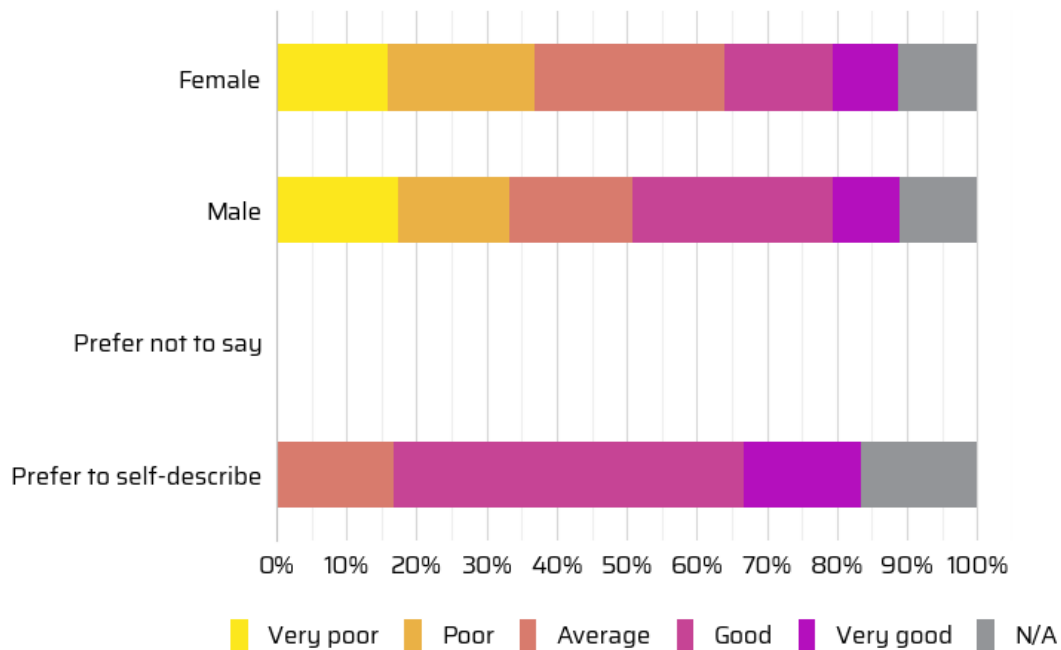


Figure 37 : Overall experience of healthcare, broken down by gender.

Table 36 : Overall experience of healthcare, broken down by gender.

Gender	Experience	Respondents	Percentage
Female	N/A	24	11.21
	Very good	20	9.35
	Good	33	15.42
	Average	58	27.1
	Poor	45	21.03
	Very poor	34	15.89
Male	N/A	7	11.11
	Very good	6	9.52
	Good	18	28.57
	Average	11	17.46
	Poor	10	15.87
Prefer not to say	Very poor	11	17.46
	N/A	0	0.0

	Very good	0	0.0
	Good	0	0.0
	Average	0	0.0
	Poor	0	0.0
	Very poor	0	0.0
	N/A	1	16.67
	Very good	1	16.67
	Good	3	50.0
Prefer to self-describe	Average	1	16.67
	Poor	0	0.0
	Very poor	0	0.0

Overall experience of health & care by employment status

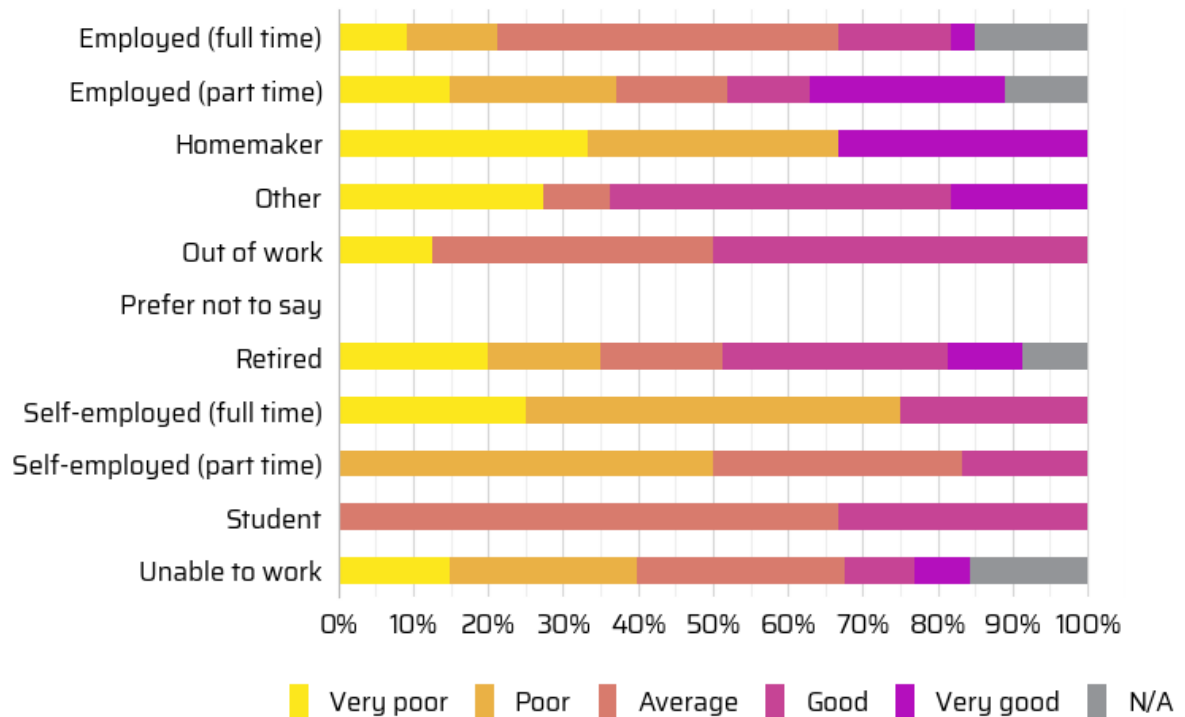


Figure 38 : Overall experience of healthcare, broken down by employment status.

Table 37 : Overall experience of healthcare, broken down by employment status.

Employment status	Experience	Respondents	Percentage
Employed (full time)	N/A	5	15.15
	Very good	1	3.03
	Good	5	15.15
	Average	15	45.45
	Poor	4	12.12
	Very poor	3	9.09
Employed (part time)	N/A	3	11.11
	Very good	7	25.93
	Good	3	11.11
	Average	4	14.81
	Poor	6	22.22
	Very poor	4	14.81
Homemaker	N/A	0	0.0
	Very good	1	33.33
	Good	0	0.0
	Average	0	0.0
	Poor	1	33.33
	Very poor	1	33.33
Other	N/A	0	0.0
	Very good	2	18.18
	Good	5	45.45
	Average	1	9.09
	Poor	0	0.0
	Very poor	3	27.27
Out of work	N/A	0	0.0
	Very good	0	0.0

	Good	4	50.0
	Average	3	37.5
	Poor	0	0.0
	Very poor	1	12.5
	N/A	0	0.0
	Very good	0	0.0
Prefer not to say	Good	0	0.0
	Average	0	0.0
	Poor	0	0.0
	Very poor	0	0.0
	N/A	7	8.75
	Very good	8	10.0
Retired	Good	24	30.0
	Average	13	16.25
	Poor	12	15.0
	Very poor	16	20.0
	N/A	0	0.0
	Very good	0	0.0
Self-employed (full time)	Good	1	25.0
	Average	0	0.0
	Poor	2	50.0
	Very poor	1	25.0
	N/A	0	0.0
	Very good	0	0.0
Self-employed (part time)	Good	1	16.67
	Average	2	33.33
	Poor	3	50.0
	Very poor	0	0.0

Student	N/A	0	0.0
	Very good	0	0.0
	Good	1	33.33
	Average	2	66.67
	Poor	0	0.0
	Very poor	0	0.0
Unable to work	N/A	17	15.74
	Very good	8	7.41
	Good	10	9.26
	Average	30	27.78
	Poor	27	25.0
	Very poor	16	14.81

Overall experience of health & care by number of dependents

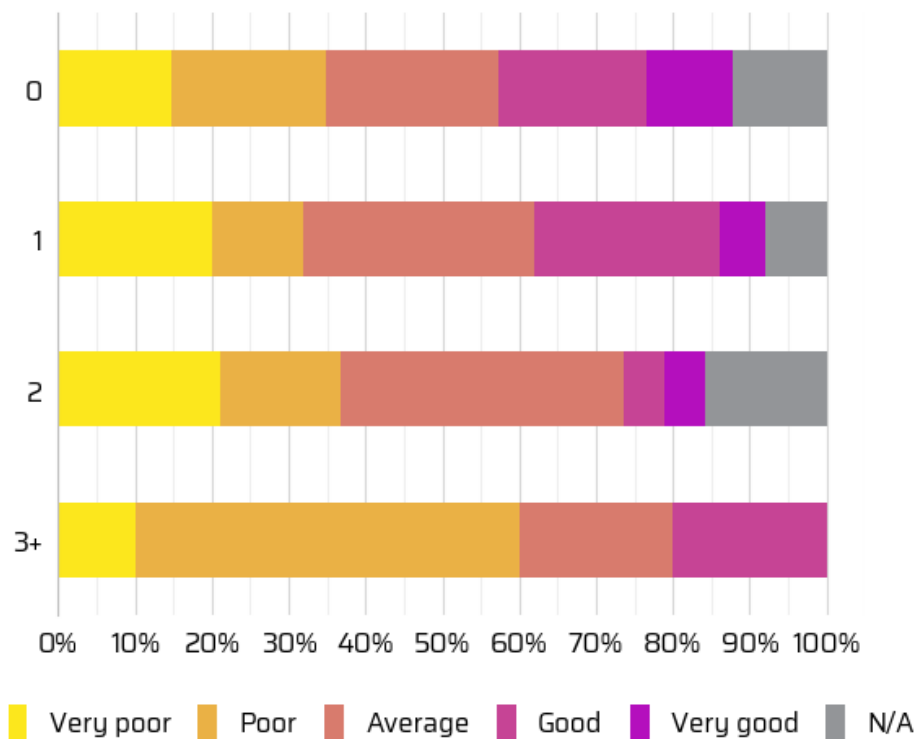


Figure 39 : Overall experience of healthcare, broken down by number of dependents.

Table 38 : Overall experience of healthcare, broken down by number of dependents.

Number of dependents	Experience	Respondents	Percentage
0	N/A	25	12.25
	Very good	23	11.27
	Good	39	19.12
	Average	46	22.55
	Poor	41	20.1
	Very poor	30	14.71
1	N/A	4	8.0
	Very good	3	6.0
	Good	12	24.0
	Average	15	30.0
	Poor	6	12.0
	Very poor	10	20.0
2	N/A	3	15.79
	Very good	1	5.26
	Good	1	5.26
	Average	7	36.84
	Poor	3	15.79
	Very poor	4	21.05
3+	N/A	0	0.0
	Very good	0	0.0
	Good	2	20.0
	Average	2	20.0
	Poor	5	50.0
	Very poor	1	10.0

Demographics

Sample size

Total number of respondents: 283

Neurological conditions

Nota bene: A single respondent may have multiple neurological conditions, therefore for this analysis the number of respondents per condition do not add up to the total number of respondents and the percentages do not add up to 100%.

A total of 164 respondents, equating to 57.95% of respondents, indicated that they have multiple (i.e., more than one) neurological conditions.

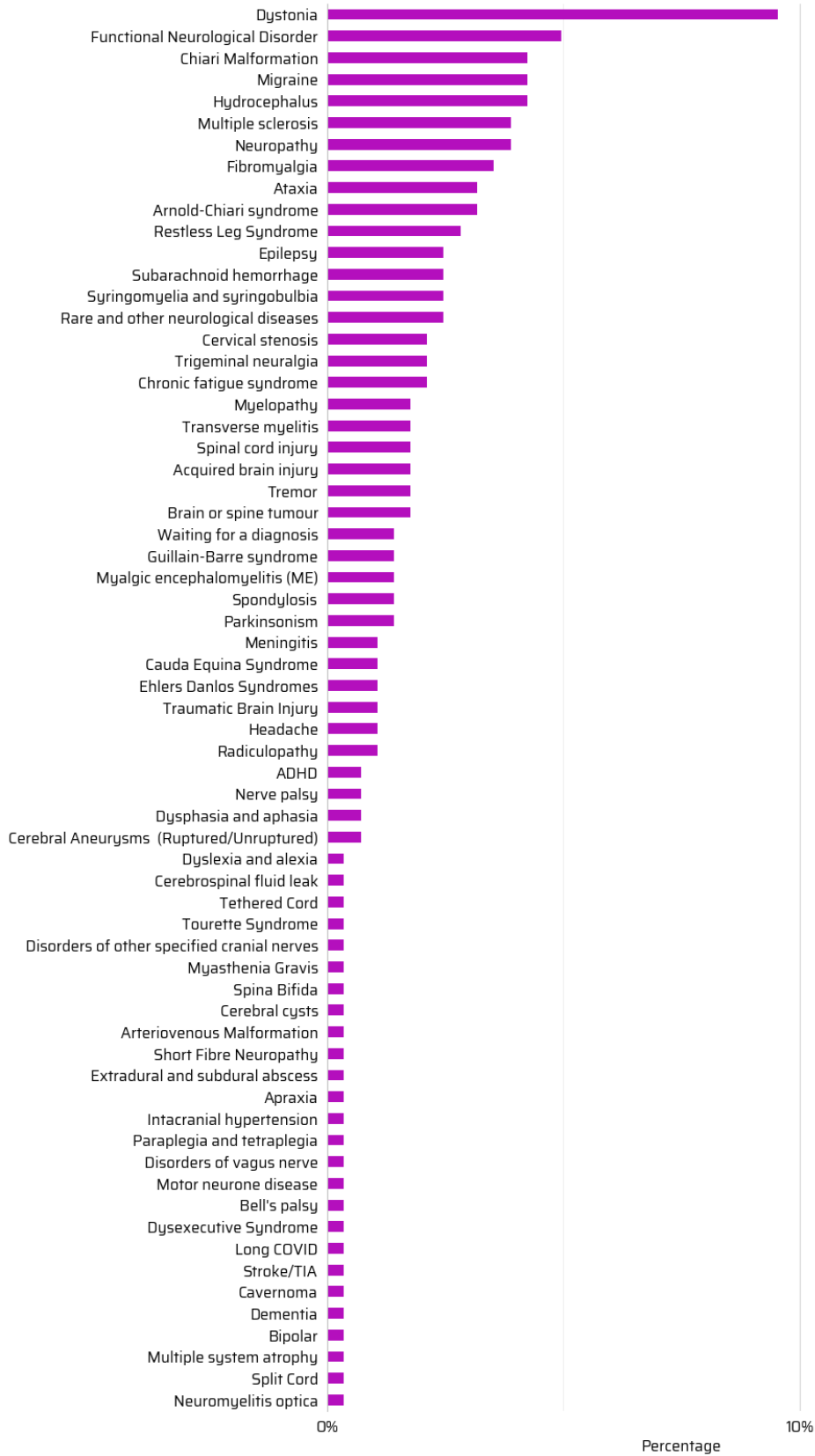


Figure 40 : Respondents had been diagnosed with neurological conditions
Brain & Spine Foundation registered charity no. 1098528

Table 39 : Respondents had been diagnosed with Neurological conditions.

Condition	Respondents	Percentage
Dystonia	27	9.54
Functional Neurological Disorder	14	4.95
Chiari Malformation	12	4.24
Migraine	12	4.24
Hydrocephalus	12	4.24
Neuropathy	11	3.89
Multiple sclerosis	11	3.89
Fibromyalgia	10	3.53
Ataxia	9	3.18
Arnold-Chiari syndrome	9	3.18
Restless Leg Syndrome	8	2.83
Epilepsy	7	2.47
Subarachnoid hemorrhage	7	2.47
Syringomyelia and syringobulbia	7	2.47
Rare and other neurological diseases	7	2.47
Chronic fatigue syndrome	6	2.12
Cervical stenosis	6	2.12
Trigeminal neuralgia	6	2.12
Myelopathy	5	1.77
Transverse myelitis	5	1.77
Spinal cord injury	5	1.77
Acquired brain injury	5	1.77
Tremor	5	1.77
Brain or spine tumour	5	1.77
Waiting for a diagnosis	4	1.41
Guillain-Barre syndrome	4	1.41
Myalgic encephalomyelitis (ME)	4	1.41

Spondylosis	4	1.41
Parkinsonism	4	1.41
Cauda Equina Syndrome	3	1.06
Ehlers Danlos Syndromes	3	1.06
Meningitis	3	1.06
Traumatic Brain Injury	3	1.06
Radiculopathy	3	1.06
Headache	3	1.06
ADHD	2	0.71
Nerve palsy	2	0.71
Dysphasia and aphasia	2	0.71
Cerebral Aneurysms (Ruptured/Unruptured)	2	0.71
Split Cord	1	0.35
Multiple system atrophy	1	0.35
Bipolar	1	0.35
Dementia	1	0.35
Cavernoma	1	0.35
Stroke/TIA	1	0.35
Long COVID	1	0.35
Dysexecutive Syndrome	1	0.35
Bell's palsy	1	0.35
Paraplegia and tetraplegia	1	0.35
Motor neurone disease	1	0.35
Disorders of vagus nerve	1	0.35
Short Fibre Neuropathy	1	0.35
Intacranial hypertension	1	0.35
Tethered Cord	1	0.35

Tourette Syndrome	1	0.35
Disorders of other specified cranial nerves	1	0.35
Myasthenia Gravis	1	0.35
Cerebrospinal fluid leak	1	0.35
Cerebral cysts	1	0.35
Arteriovenous Malformation	1	0.35
Spina Bifida	1	0.35
Extradural and subdural abscess	1	0.35
Apraxia	1	0.35
Dyslexia and alexia	1	0.35
Neuromyelitis optica	1	0.35

Multiple neurological conditions

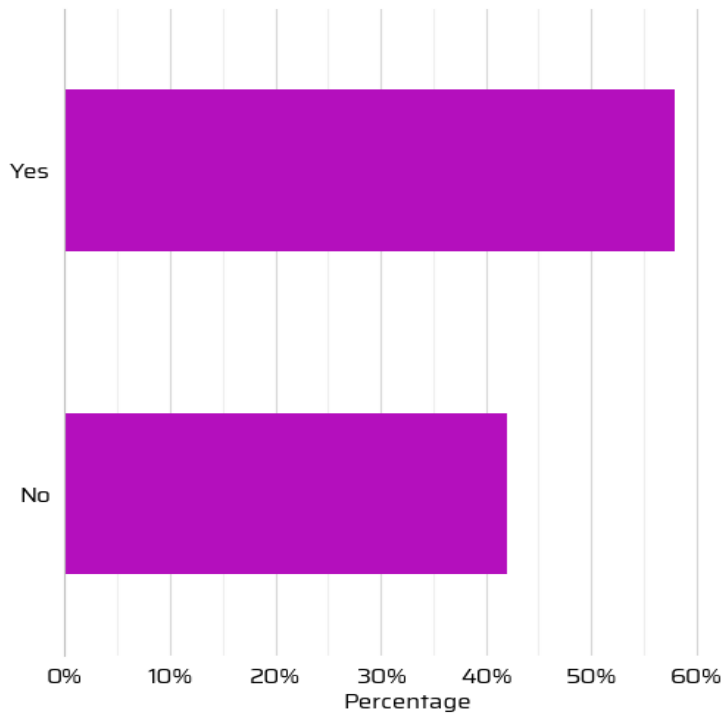


Figure 41: Whether respondents were diagnosed with multiple neurological conditions.

Table 40 : Whether respondents were diagnosed with multiple neurological conditions.

Multiple neurological conditions	Respondents	Percentage
Yes	164	57.95
No	119	42.05

Number of non-neurological co-occurring conditions

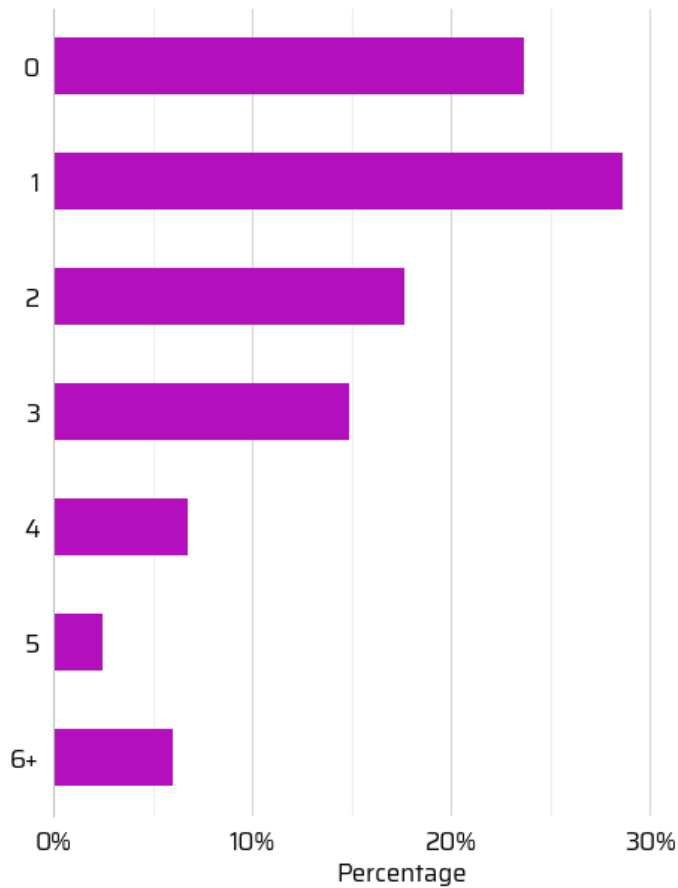


Figure 42 : Number of non-neurological conditions that respondents were diagnosed with that co-occur with their neurological condition(s).

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

Number of conditions	Respondents	Percentage
0	67	23.67

1	81	28.62
2	50	17.67
3	42	14.84
4	19	6.71
5	7	2.47
6+	17	6.01

Age

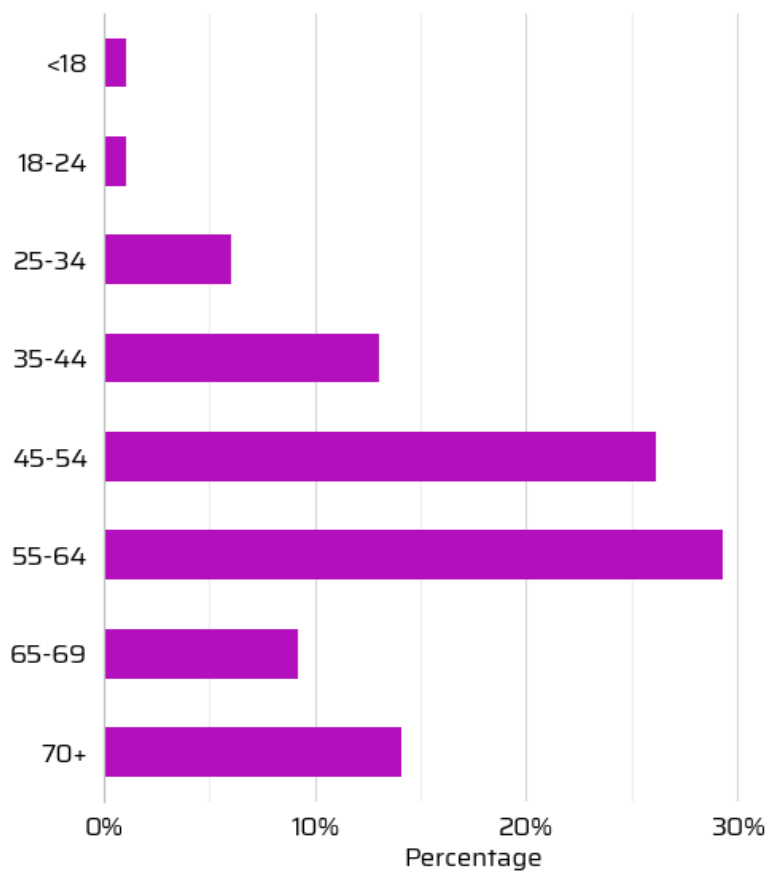


Figure 43 : Age of respondents.

Table 42 : Age of respondents.

Age	Respondents	Percentage
<18	3	1.06
18-24	3	1.06

25-34	17	6.01
35-44	37	13.07
45-54	74	26.15
55-64	83	29.33
65-69	26	9.19
70+	40	14.13

Gender

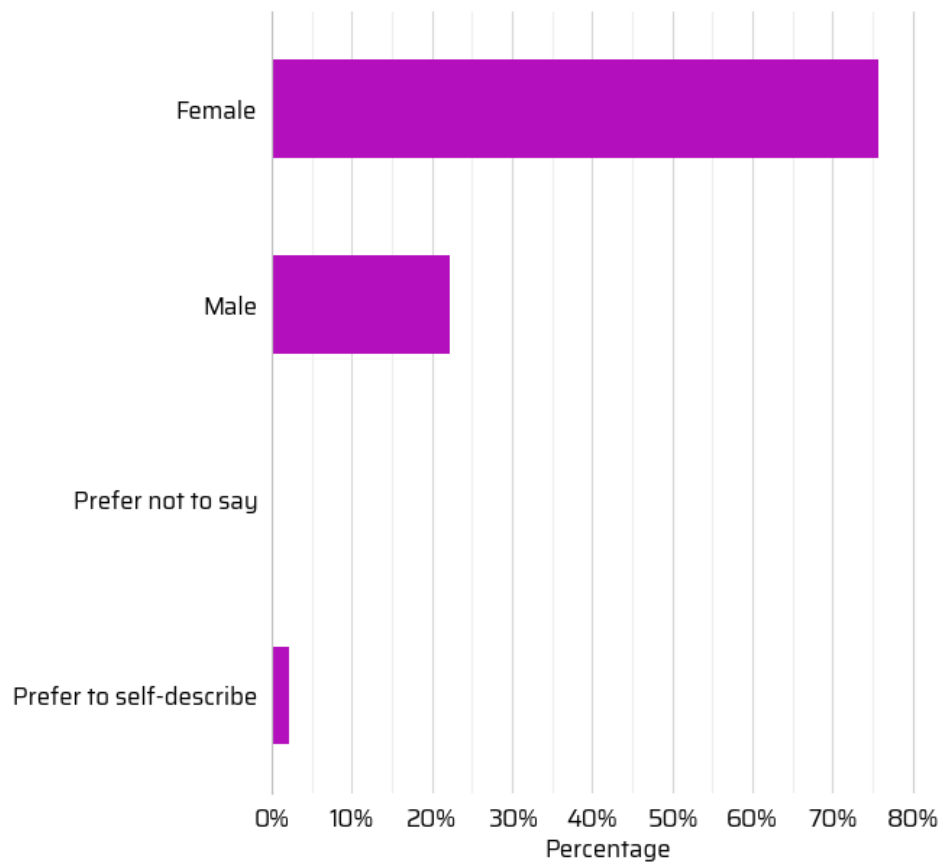


Figure 44 : Gender of respondents.

Table 43 : Gender of respondents.

Gender	Respondents	Percentage
Female	214	75.62
Male	63	22.26
Prefer not to say	0	0.0

Prefer to self-describe	6	2.12
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Sexual orientation

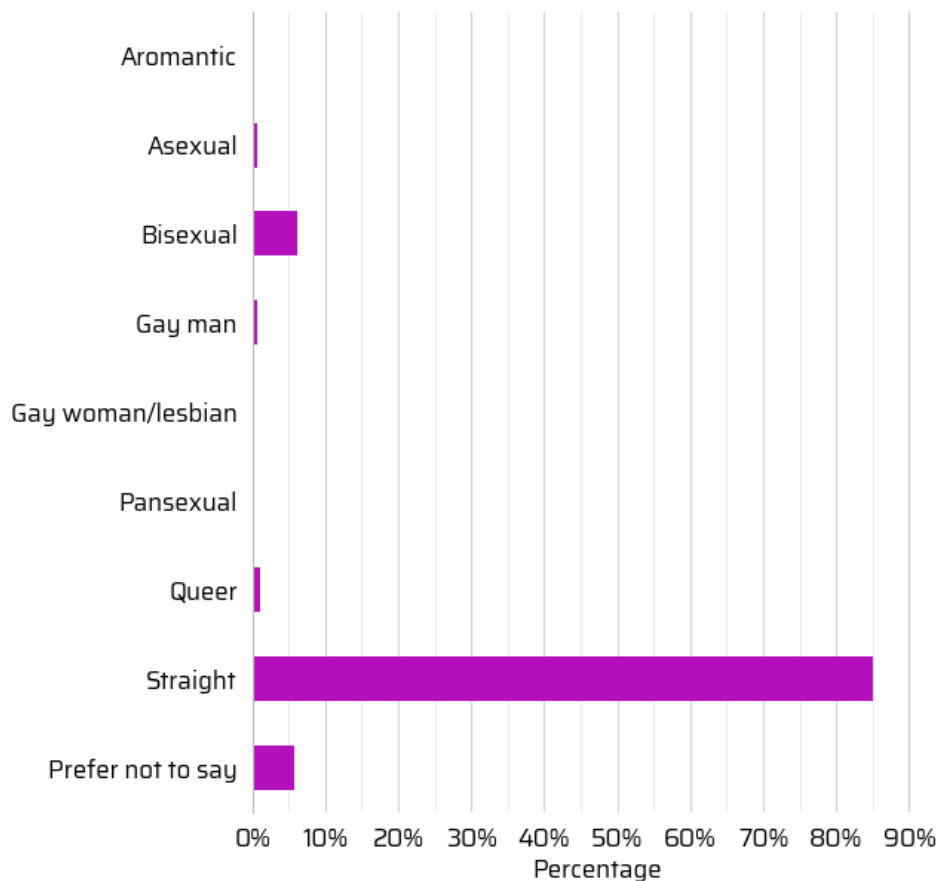


Figure 45 : Sexual orientation of respondents.

Table 44 : Sexual orientation of respondents.

Sexual orientation	Respondents	Percentage
Aromantic	1	0.36
Asexual	2	0.72
Bisexual	17	6.09
Gay man	2	0.72
Gay woman/lesbian	1	0.36
Pansexual	0	0.0
Queer	3	1.08

Straight	237	84.95
Prefer not to say	16	5.73

Age at diagnosis

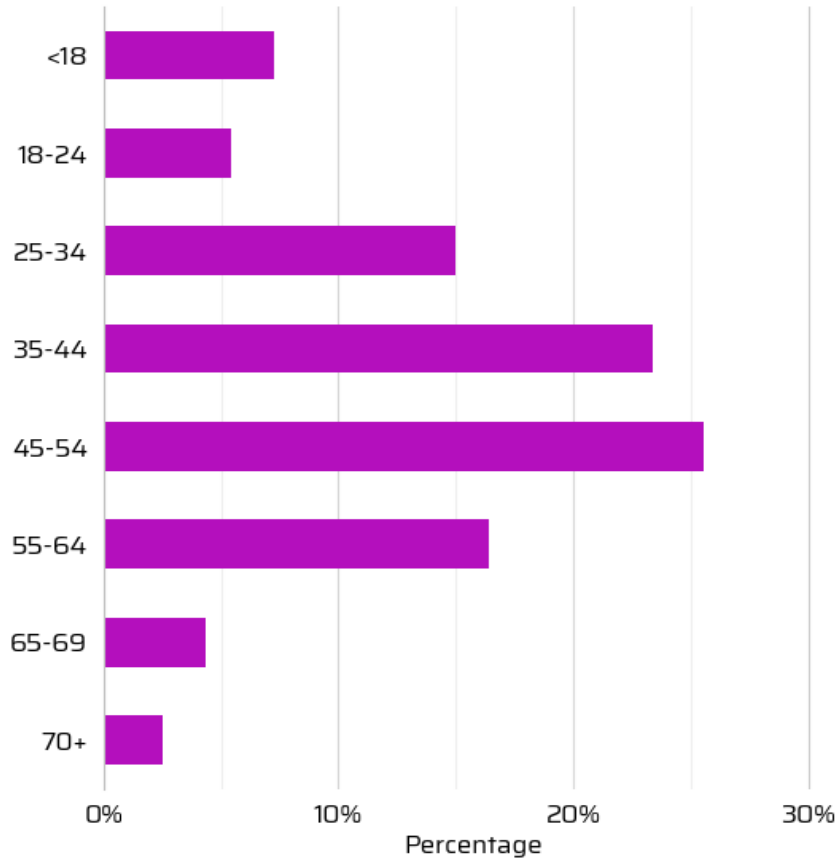


Figure 46 : Age of respondents when they were first diagnosed with a neurological condition.

Table 45 : Age of respondents when they were first diagnosed with a neurological condition.

Age	Respondents	Percentage
<18	20	7.3
18-24	15	5.47
25-34	41	14.96
35-44	64	23.36
45-54	70	25.55
55-64	45	16.42

65-69	12	4.38
70+	7	2.55

Location of respondents

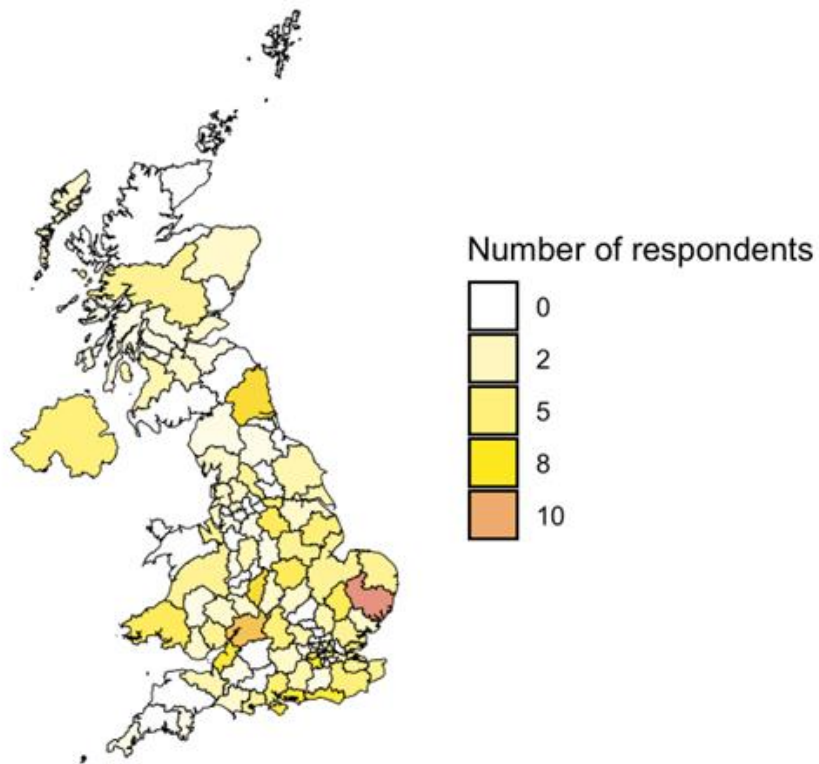


Figure 47 : Location of respondents.

Table 46 : Location of respondents.

Area Name	Postal Area	Number of respondents
Ipswich	IP	11
Gloucester	GL	9
Birmingham	B	8
Newcastle upon Tyne	NE	8
Brighton	BN	7
Bristol	BS	7

Kingston upon Thames	KT	7
Portsmouth	PO	7
Cambridge	CB	6
London - E	E	6
Leicester	LE	6
Sheffield	S	6
Swansea	SA	6
Lincoln	LN	5
Oxford	OX	5
Southampton	SO	5
Southend-on-Sea	SS	5
Tonbridge	TN	5
Twickenham	TW	5
Wakefield	WF	5
Northern Ireland	BT	5
Bradford	BD	4
Bournemouth	BH	4
Chester	CH	4
Chelmsford	CM	4
Canterbury	CT	4
Medway	ME	4
Nottingham	NG	4
Newport	NP	4
Norwich	NR	4
Peterborough	PE	4
Perth	PH	4
Shrewsbury	SY	4
Guildford	GU	3

Hemel Hempstead	HP	3
Hull	HU	3
Kilmarnock	KA	3
Stevenage	SG	3
Stoke-on-Trent	ST	3
London - SW	SW	3
Taunton	TA	3
York	YO	3
Aberdeen	AB	2
Blackburn	BB	2
Bolton	BL	2
Cardiff	CF	2
Colchester	CO	2
Croydon	CR	2
Coventry	CV	2
Dartford	DA	2
Doncaster	DN	2
Dorchester	DT	2
Harrow	HA	2
Hereford	HR	2
Outer Hebrides	HS	2
Kirkcaldy	KY	2
Liverpool	L	2
Lancaster	LA	2
Motherwell	ML	2
London - N	N	2
Northampton	NN	2
Preston	PR	2

Reading	RG	2
London - SE	SE	2
Worcester	WR	2
Bath	BA	1
Bromley	BR	1
Carlisle	CA	1
Derby	DE	1
Darlington	DL	1
Dudley	DY	1
Edinburgh	EH	1
Falkirk	FK	1
The Fylde	FY	1
Glasgow	G	1
Llandrindod Wells	LD	1
London - NW	NW	1
Paisley	PA	1
Redhill	RH	1
Stockport	SK	1
Slough	SL	1
Sutton	SM	1
Telford	TF	1
Torquay	TQ	1
Truro	TR	1
Uxbridge	UB	1
London - W	W	1
Warrington	WA	1
St Albans	AL	0
Crewe	CW	0

Dundee	DD	0
Dumfries and Galloway	DG	0
Durham	DH	0
London - EC	EC	0
Enfield	EN	0
Exeter	EX	0
Huddersfield	HD	0
Harrogate	HG	0
Halifax	HX	0
Ilford	IG	0
Inverness	IV	0
Kirkwall	KW	0
Llandudno	LL	0
Leeds	LS	0
Luton	LU	0
Manchester	M	0
Milton Keynes	MK	0
Oldham	OL	0
Plymouth	PL	0
Romford	RM	0
Swindon	SN	0
Salisbury	SP	0
Sunderland	SR	0
Teviotdale	TD	0
Teeside	TS	0
London - WC	WC	0
Watford	WD	0
Wigan	WN	0

Walsall	WS	0
Wolverhampton	WV	0
Lerwick	ZE	0

NB: 5 respondents did not provide a UK-based postcode (or did not provide one) and are hence not included in this map and table.

Employment status

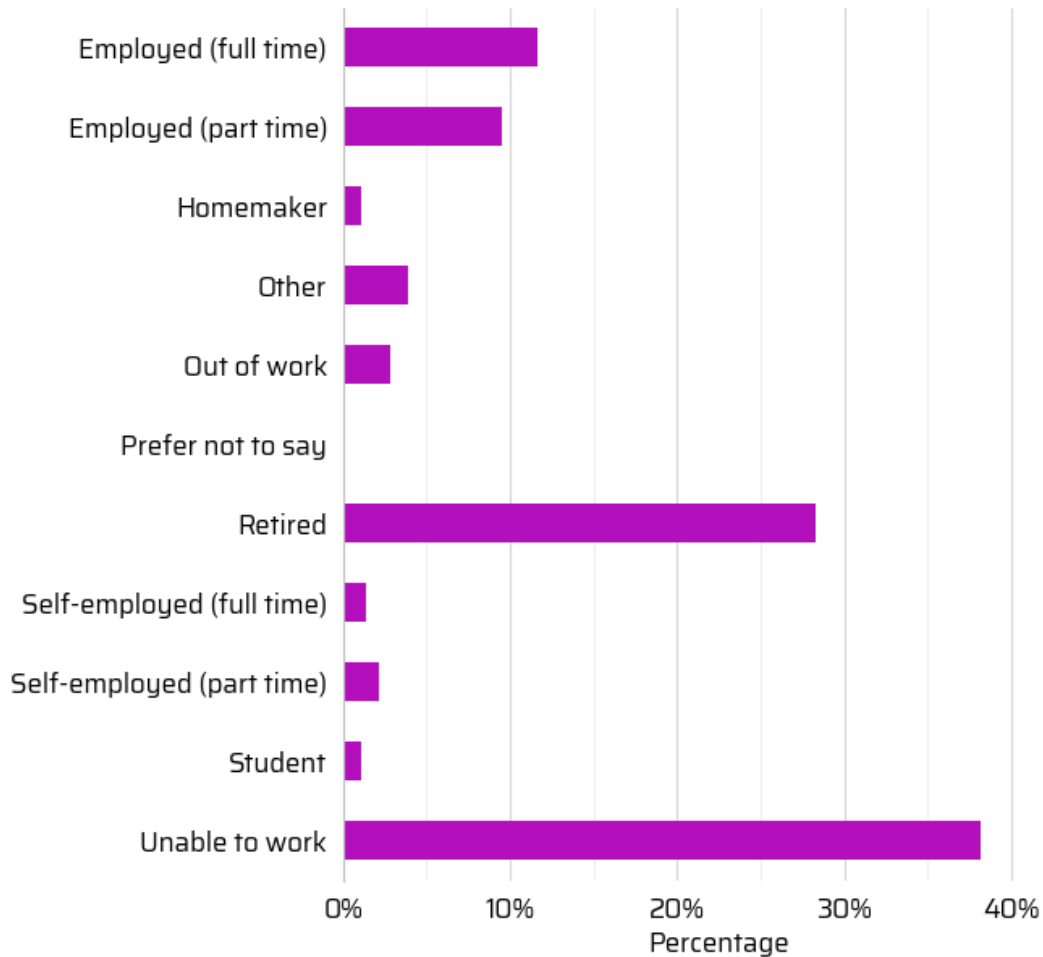


Figure 48 : Employment status of respondents.

Table 47 : Employment status of respondents.

Employment status	Respondents	Percentage
Employed (full time)	33	11.66
Employed (part time)	27	9.54

Homemaker	3	1.06
Other	11	3.89
Out of work	8	2.83
Prefer not to say	0	0.0
Retired	80	28.27
Self-employed (full time)	4	1.41
Self-employed (part time)	6	2.12
Student	3	1.06
Unable to work	108	38.16

Ethnic group

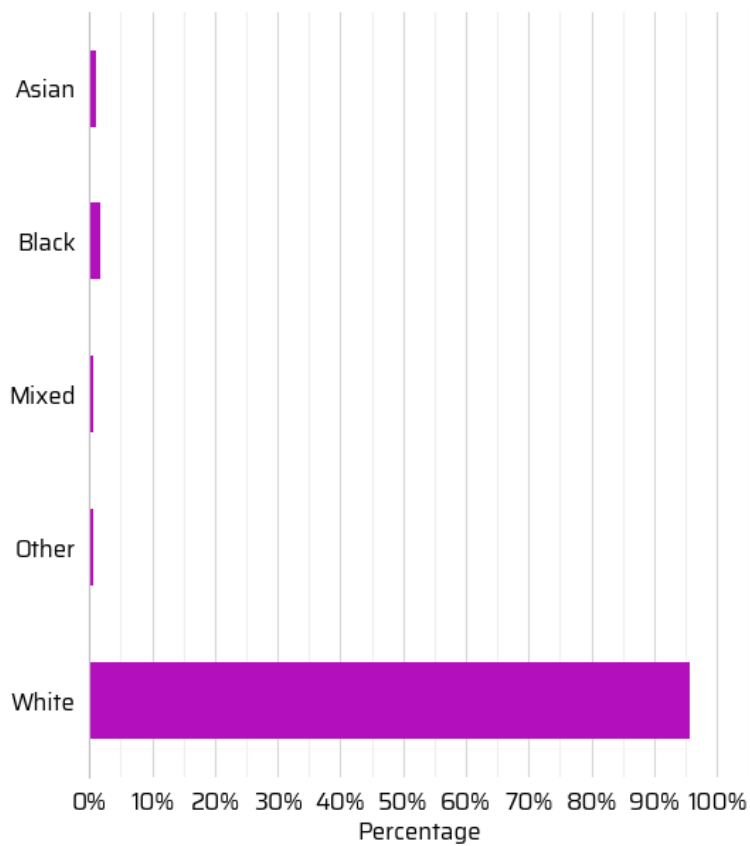


Figure 49 : Ethnic group of respondents.

Table 48 : Ethnic group of respondents.

Ethnic group	Respondents	Percentage
Asian	3	1.06
Black	5	1.77
Mixed	2	0.71
Other	2	0.71
White	271	95.76

Number of dependents

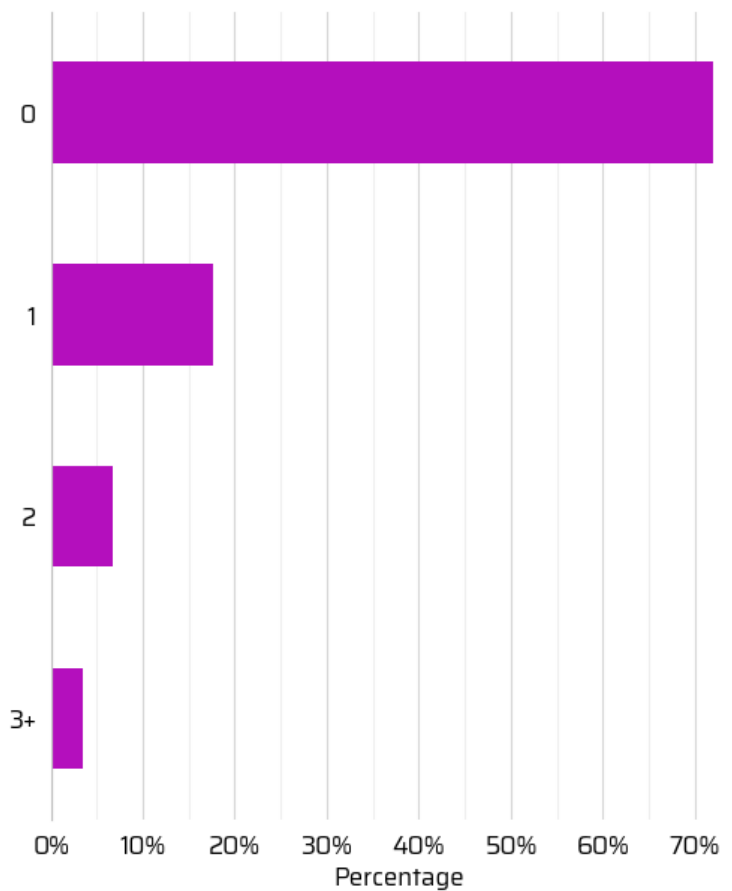


Figure 50 : Number of dependents of respondents.

Table 49 : Number of dependents of respondents.

Number of dependents	Respondents	Percentage
0	204	72.08

1	50	17.67
2	19	6.71
3+	10	3.53

Receiving care or support

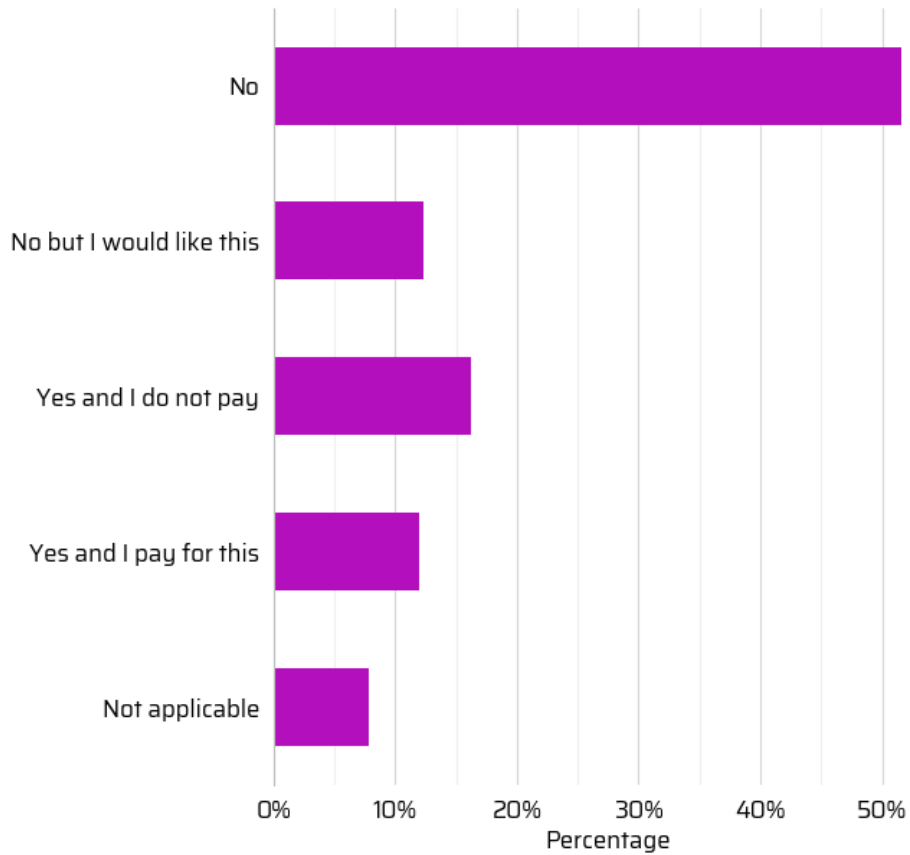


Figure 51 : Whether respondents receiving care or support.

Table 50 : Whether respondents receiving care or support.

Receive care/support	Respondents	Percentage
No	146	51.59
No but I would like this	35	12.37
Yes and I do not pay	46	16.25
Yes and I pay for this	34	12.01
Not applicable	22	7.77

Table 51

Appendix A - Survey Questions

Question	Response options		
Are you filling in this questionnaire for yourself?	Yes	No	
About your condition(s)			
Which year were you diagnosed with your primary neurological condition?	Free text		
Which year were you diagnosed with your primary neurological condition?	Free text		
Please tell us your first neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms		
Do you have any other neurological condition(s) and/or symptoms you would like to add?	Yes	No	
Please tell us a second neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms		
Do you have any other neurological condition(s) and/or symptoms you would like to add?	Yes	No	
Please tell us a third neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms		
Do you have any other neurological condition(s) and/or symptoms you would like to add?	Yes	No	
Please tell us a fourth neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms		
Do you have any other neurological condition(s) and/or symptoms you would like to add?	Yes	No	
Please tell us a fifth neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms		
Do you have any other neurological condition(s) and/or symptoms you would like to add?	Yes	No	
Please tell us a sixth neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms		
Do you live with conditions other than your neurological condition(s)? If so, how many:	None	1	2
	4	5	6+
Thinking about your health and care for your neurological condition(s), to what extent do you agree with the following statements?			
I feel listened to by my health and care professionals	Strongly agree	Agree	Neither agree nor disagree
	Disagree	Strongly	Not applicable
I know who to contact if I have a question about my neurological condition or if it changes	Same as above		
While I wait for the treatment and care that I need, I am kept informed and feel supported	Same as above		
What are your priorities for the NHS?	Same as above		
Why did you choose these priorities?	Free text		
About your recent experiences of treatment and support.			

Overall, how would you describe your experience of health or care in the last eight weeks?	Very good	Good	Average	Poor
	Very Poor	N/A		
Last time you wanted to see or speak to a specialist about your neurological condition, what did you want to do?	See a specialist at the clinic			
	Speak to a specialist on the phone			
	Have someone visit me at my home			
	I didn't mind / wasn't sure what I wanted			
Were you about to speak to or see a specialist?	Yes	No		
How convenient was the appointment you were able to get?	Very convenient	Fairly convenient	Not very convenient	Not at all convenient
If you were not able to get an appointment or the appointment you were offered wasn't convenient, why was that?	There weren't any appointments for the day.			
	There weren't any appointments for the time I wanted			
	I could not see my preferred specialist			
	I could not book ahead			
	Another reason			
Please tell us the reason why you could not get an appointment or were not offered a convenient one.	Free text			
What did you do on that occasion?	Went to the appointment I was offered.			
	Got an appointment for a different day.			
	Had a consultation over the phone.			
	Went to A&E / a walk-in centre.			
	Saw a pharmacist			
	Decided a contact my specialist another time			
	Didn't see or speak to anyone			
How many times have you sought A&E/emergency support from the NHS as a result of your neurological condition in the last eight weeks?	None	1-2 times	3-5 times	5 or more times
Have you had any medical appointments (including remote appointments) in the last eight weeks?	Yes	No	Don't Know	
How many medical appointments have you had in the last eight weeks?	0	1	2	3

	4	5	6+
Who was your first medical appointment with?	Neurologist		
	Specialist Nurse		
	Physiotherapist		
	Speech and Language Therapist		
	Occupational Therapist		
	Psychologist/ Psychiatrist		
	GP		
	Social Services		
	Neurosurgery		
	Other Allied Health Professional (AHP)		
	Other		
How was your first medical appointment delivered?	Phone		
	Videoconference		
	Via text/WhatsApp		
	Face to face		
	Other		
How helpful was your first medical appointment?	It was helpful		
	It was not helpful		
	Don't Know		
Who was your second medical appointment with?	Neurologist		
	Specialist Nurse		
	Physiotherapist		
	Speech and Language Therapist		
	Occupational Therapist		
	Psychologist/ Psychiatrist		
	GP		
	Social Services		

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

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

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

How helpful was your sixth medical appointment?	It was helpful
	It was not helpful
	Don't Know
To what extent do you feel your mental wellbeing needs are being met?	To a great extent
	To a moderate extent
	To a small extent
	Not at all
	Don't Know
Which of the following describes how you feel at the moment?	Calm
	Well supported
	Anxious
	Hopeless
	Lonely
About you	
What year were you born?	Free text
To which of these ethnic groups do you belong?	White British
	White Irish
	Any other White background
	White and Black Caribbean
	White and Asian
	Any other mixed background
	Indian
	Pakistani
	Bangladeshi
	Any other Asian background
	Caribbean
	African
	Any other Black background

	Chinese
	Any other ethnic background
What is your gender?	Male
	Female
	Prefer to self-describe
	Prefer not to say
What is your sexual orientation?	Aromantic
	Asexual
	Bisexual
	Gay man
	Gay woman/lesbian
	Pansexual
	Queer
	Straight (heterosexual)
	Prefer not to say
Other	
What best describes your employment status?	Employed (full time)
	Employed (part time)
	Self-employed (full-time)
	Self-employed (part-time)
	Homemaker

Appendix B - List of Conditions

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-Séguard syndrome	Cauda Equina Syndrome	Cavernoma
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	Clonic hemifacial spasm
Cranial nerve disorder	Creutzfeldt-Jakob disease	Cysticercosis of central nervous system	Dementia	Demyelinating disease
Disorder of visual pathways	Disorders of hypoglossal nerve	Disorders of multiple cranial nerves	Disorders of olfactory nerve	Disorders of optic chiasm
Disorders of other specified cranial nerves	Disorders of other visual pathways	Disorders of vagus nerve	Disorders of visual cortex	Down's Syndrome
Dysarthria and anarthria	Dysexecutive Syndrome	Dyslexia and alexia	Dysphasia and aphasia	Dystonia
Eaton-Lambert syndrome	Ehlers Danlos Syndromes	Encephalitis	Epidemic vertigo	Epilepsy
Extradural and subdural abscess	Extrapyramidal disorder	Facial myokymia	Faetal Alcohol Spectrum Disorders (FASD)	Fibromyalgia
Functional Neurological Disorder	Geniculate ganglionitis	Guillain-Barre syndrome	Headache	Hemicranial Corrina
Hemiplegia	Hereditary Spastic Paralegia	Huntington's disease	Hydrocephalus	Hydromyelia

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	Malaria	Melkersson's syndrome
Meningeal tuberculoma	Meningitis	Migraine	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 palsy	Nerve Tumour	Neurofibromatosis	Neuromyelitis optica	Neuropathy
No diagnosis	Optic atrophy	Papilloedema	Paraplegia and tetraplegia	Parkinsonism
Post-polio syndrome	Postzoster neuralgia	Progressive multifocal leukoencephalopathy	Rabies	Radiculopathy
Rare and other neurological diseases	Rare and other neurological diseases	Refsum's Disease	Restless Leg Syndrome	Short Fibre Neuropathy
Spina Bifida	Spinal cord injury	Spinal muscular atrophy	Split Cord	Spondylosis
Stroke/TIA	Subacute sclerosing panencephalitis	Subarachnoid hemorrhage	Syringomyelia and syringobulbia	Tarlov Cysts
Tethered Cord	Tourette Syndrome	Toxic encephalopathy	Toxoplasma meningoencephalitis	Transverse myelitis
Traumatic Brain Injury	Tremor	Trigeminal neuralgia	Tuberculous meningitis	Vascular myelopathies
Waiting for a diagnosis				