



NeuroLifeNow

May - June 2023 Report

Work experiences



About NeuroLifeNow

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

NeuroLifeNow 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.

NeuroLifeNow has enabled us to unify and amplify your voices to drive improvements that will transform the lives of millions.

Foreword

Every aspect of your life can be impacted by living with a neurological condition, and this is particularly true of work. Far too often, we hear from people who have not received the right support from their employer, aren't able to access the right adjustments for work, or aren't aware of the financial support they are entitled to. At worst, we hear about the stigma and discrimination people face in the workplace due to their neurological condition.

“I was bullied out of every single work job I ever had, purely because all colleagues could never be bothered to assist me during any of my lifelong fully uncontrollable epilepsy seizures.”

That's why we wanted to take a deeper dive into the relationship between work and living with a neurological condition this summer. One in five told us that they had to leave their job because their employer failed to make the right reasonable adjustments. 4 in 10 said their manager and/or colleagues did not understand the challenges of living with a neurological condition. A quarter had experienced discrimination in the workplace. This has to change.

“I cannot financially survive on benefits and pay for the costs associated with being unwell as well as paying for care. I try to remain positive but it's a very bleak and isolating existence.”

You also told us about the impact of leaving work. About the loss of identity many experienced, and huge impacts on self-esteem. All of this could be avoided, with the right support to get into the right employment, the right adjustments and attitudes to enable people to stay in work as long as possible and the right support to leave work “well”.

“It's hard. Really hard. I've gone from being on top of my game to what feels like the bottom of the pile and it's heartbreaking.”

Your insights and evidence have informed a new programme to address these issues in the workplace. The Brain and Spine Foundation will launch this initiative in 2023 so that people affected by neurological conditions receive the support they need and deserve.

“It's so hard to explain to colleagues that for me to walk somewhere else in the building is like them running a marathon. People also struggle to understand the variability of my condition or how getting a cold affects me compared to them.”

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

This report focuses on the findings of the survey running over May and June 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 experiences of work.

Key Findings

- **371 respondents** completed the May-June 2023 survey, with **67 conditions represented**. The top 3 most frequently reported conditions are Dystonia, multiple sclerosis (MS) and Functional Neurological Disorder (FND).
- **37.44% said they had not been able to continue to work** due to their neurological condition.
- **21.83% said they had to leave a job because of their employer's failure to make reasonable adjustments**. People living with multiple neurological conditions or conditions other than their neurological conditions were more likely to report this.
- **26.81% said they had been discriminated against at work** due to attitudes towards their neurological condition. Females, people living with multiple neurological conditions or conditions other than their neurological conditions were more likely to report this.
- **People told us about the challenges they had experienced at work**. Five themes emerged, including changes in employment status (due to their neurological condition), an impact on their ability to work, impacts on their mental health, a lack of support from their workplace and little to no impact (for example, due to flexible working arrangements already being in place).
- **36.73% said their experience of health and care in May and June was good or very good**.
- **42.36% said their mental health needs were not being met at all**.
- You told us about 373 appointments with health and care professionals. **74.26% of those appointments were considered helpful**.
- More than 4 out of 10 (43.97%) of appointments were with a GP. **20.35% of appointments were held over the phone**.

Workplace experiences

Overall experience of the workplace

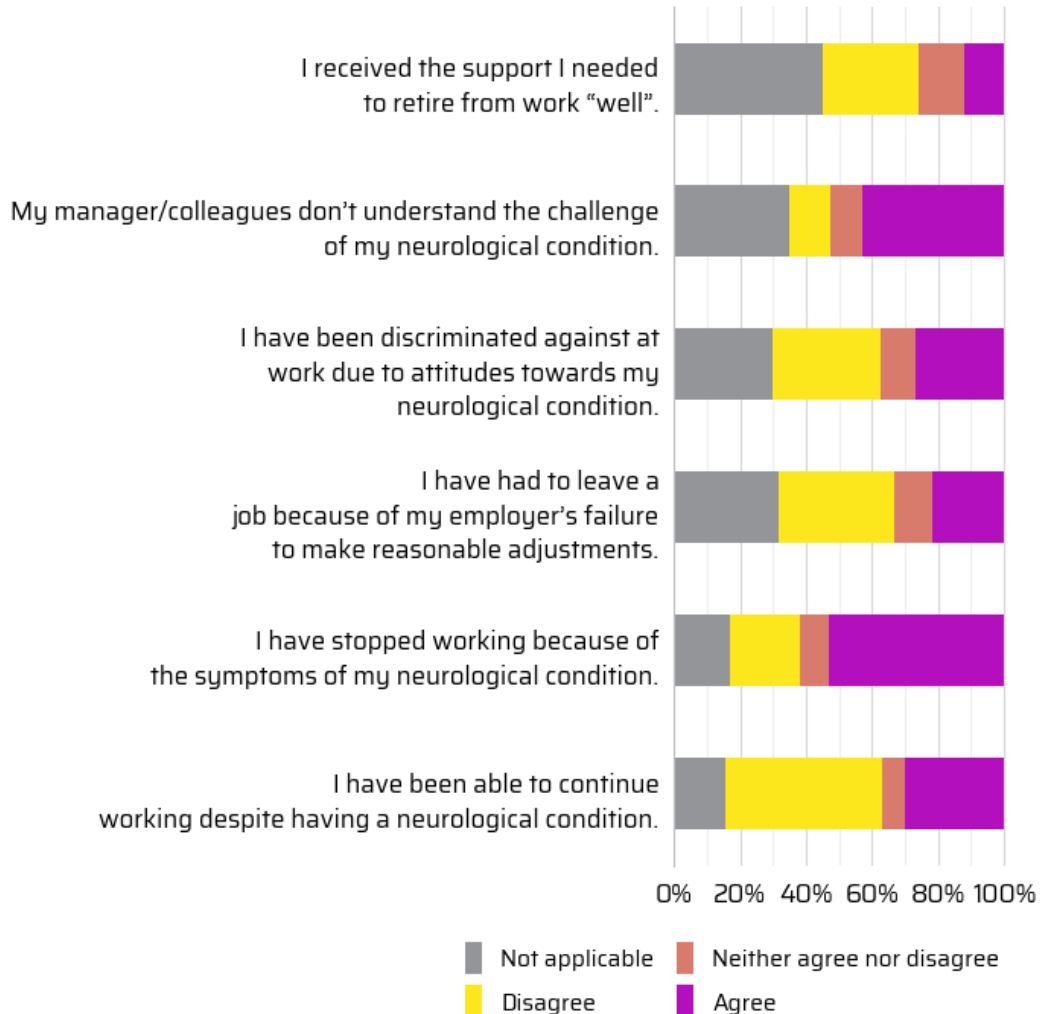


Figure 1 : Workplace experience: overall.

Table 1 : Workplace experience: overall.

Workplace experience	Response	Respondents	Percentage
I have been able to continue working despite having a neurological condition.	Agree	112	30.19
	Neither agree nor disagree	25	6.74
	Disagree	176	47.44
	Not applicable	58	15.63
	Agree	197	53.24

I have stopped working because of the symptoms of my neurological condition.	Neither agree nor disagree	31	8.38
	Disagree	79	21.35
	Not applicable	63	17.03
I have had to leave a job because of my employer's failure to make reasonable adjustments.	Agree	81	21.83
	Neither agree nor disagree	42	11.32
	Disagree	130	35.04
	Not applicable	118	31.81
I have been discriminated against at work due to attitudes towards my neurological condition.	Agree	100	26.81
	Neither agree nor disagree	39	10.46
	Disagree	122	32.71
	Not applicable	112	30.03
My manager/colleagues don't understand the challenge of my neurological condition.	Agree	159	42.86
	Neither agree nor disagree	37	9.97
	Disagree	45	12.13
	Not applicable	130	35.04
I received the support I needed to retire from work "well".	Agree	45	12.1
	Neither agree nor disagree	51	13.71
	Disagree	109	29.3
	Not applicable	167	44.89

Workplace experience among those with vs without multiple neurological conditions.

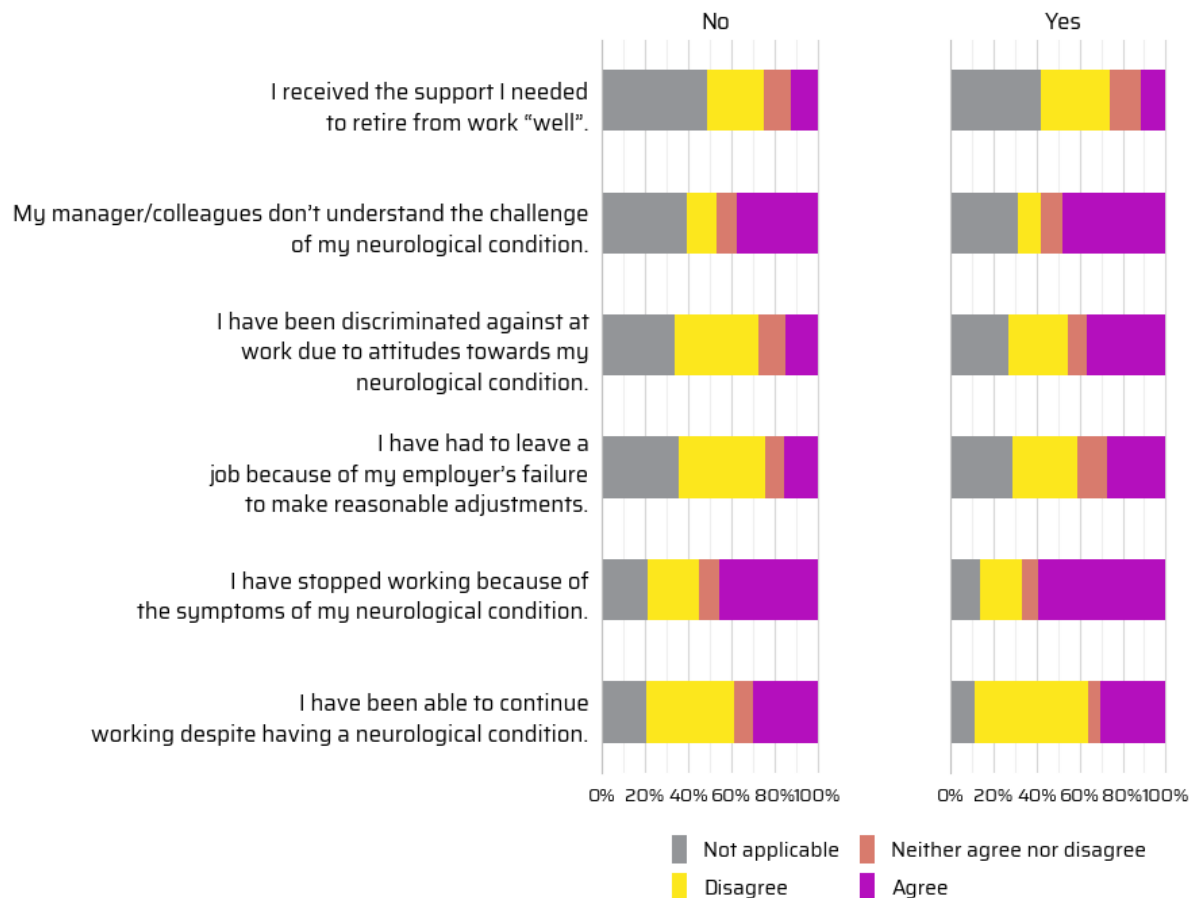


Figure 2 : Workplace experience among people with vs without multiple neurological conditions.

Table 2 : Workplace experience among people with vs without multiple neurological conditions.

Multiple neurological conditions	Workplace experience	Response	Respondents	Percentage
Yes	I have been able to continue working despite having a neurological condition.	Agree	62	30.39
		Neither agree nor disagree	11	5.39
		Disagree	108	52.94
		Not applicable	23	11.27
		Agree	120	59.11

I have stopped working because of the symptoms of my neurological condition.	Neither agree nor disagree	16	7.88
	Disagree	39	19.21
	Not applicable	28	13.79
I have had to leave a job because of my employer's failure to make reasonable adjustments.	Agree	55	27.09
	Neither agree nor disagree	28	13.79
	Disagree	62	30.54
I have been discriminated against at work due to attitudes towards my neurological condition.	Not applicable	58	28.57
	Agree	75	36.59
	Neither agree nor disagree	18	8.78
My manager/colleagues don't understand the challenge of my neurological condition.	Disagree	57	27.8
	Not applicable	55	26.83
	Agree	97	47.78
I received the support I needed to retire from work "well".	Neither agree nor disagree	21	10.34
	Disagree	21	10.34
	Not applicable	64	31.53
No	Agree	23	11.27
	Neither agree nor disagree	30	14.71
	Disagree	65	31.86
	Not applicable	86	42.16
	Agree	50	30.12

I have been able to continue working despite having a neurological condition.	Neither agree nor disagree	14	8.43
	Disagree	68	40.96
	Not applicable	34	20.48
I have stopped working because of the symptoms of my neurological condition.	Agree	76	45.78
	Neither agree nor disagree	15	9.04
	Disagree	40	24.1
I have had to leave a job because of my employer's failure to make reasonable adjustments.	Not applicable	35	21.08
	Agree	26	15.57
	Neither agree nor disagree	14	8.38
I have been discriminated against at work due to attitudes towards my neurological condition.	Disagree	68	40.72
	Not applicable	59	35.33
	Agree	25	14.97
My manager/colleagues don't understand the challenge of my neurological condition.	Neither agree nor disagree	21	12.57
	Disagree	65	38.92
	Not applicable	56	33.53
	Agree	62	37.13
	Neither agree nor disagree	16	9.58
	Disagree	23	13.77
	Not applicable	66	39.52
	Agree	21	12.57

I received the support I needed to retire from work "well".	Neither agree nor disagree	21	12.57
	Disagree	44	26.35
	Not applicable	81	48.5

Workplace experience among people with vs without co-occurring non-neurological condition.

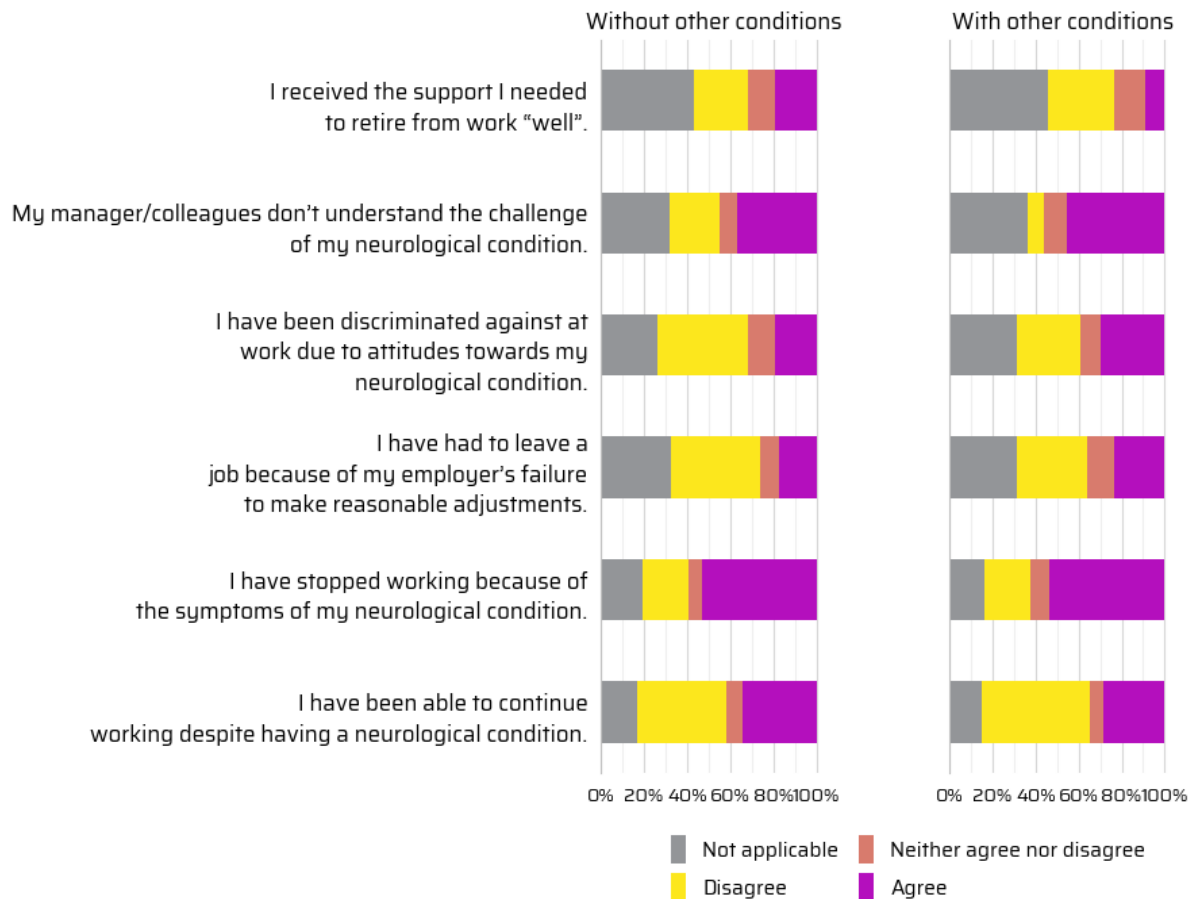


Figure 3 : Workplace experience among people with vs without co-occurring non-neurological conditions.

Table 3 : Workplace experience among people with vs without co-occurring non-neurological conditions.

Co-occurring conditions	Workplace experience	Response	Respondents	Percentage
		Agree	77	28.73

With other conditions	I have been able to continue working despite having a neurological condition.	Neither agree nor disagree	17	6.34
		Disagree	133	49.63
		Not applicable	41	15.3
	I have stopped working because of the symptoms of my neurological condition.	Agree	142	53.38
		Neither agree nor disagree	24	9.02
		Disagree	57	21.43
	I have had to leave a job because of my employer's failure to make reasonable adjustments.	Not applicable	43	16.17
		Agree	63	23.6
		Neither agree nor disagree	33	12.36
	I have been discriminated against at work due to attitudes towards my neurological condition.	Disagree	87	32.58
		Not applicable	84	31.46
		Agree	80	29.74
	My manager/colleagues don't understand the challenge of my neurological condition.	Neither agree nor disagree	26	9.67
		Disagree	78	29.0
		Not applicable	85	31.6
	I received the support I needed to retire from work "well".	Agree	121	45.32
		Neither agree nor disagree	28	10.49
		Disagree	21	7.87
	Not applicable	97	36.33	
	Agree	25	9.33	
	Neither agree nor disagree	38	14.18	
	Disagree	83	30.97	
	Not applicable	122	45.52	
	Agree	35	33.98	

Without other conditions	I have been able to continue working despite having a neurological condition.	Neither agree nor disagree	8	7.77
		Disagree	43	41.75
		Not applicable	17	16.5
	I have stopped working because of the symptoms of my neurological condition.	Agree	55	52.88
		Neither agree nor disagree	7	6.73
		Disagree	22	21.15
	I have had to leave a job because of my employer's failure to make reasonable adjustments.	Not applicable	20	19.23
		Agree	18	17.31
		Neither agree nor disagree	9	8.65
	I have been discriminated against at work due to attitudes towards my neurological condition.	Disagree	43	41.35
		Not applicable	34	32.69
		Agree	20	19.23
	My manager/colleagues don't understand the challenge of my neurological condition.	Neither agree nor disagree	13	12.5
		Disagree	44	42.31
		Not applicable	27	25.96
	I received the support I needed to retire from work "well".	Agree	38	36.54
Neither agree nor disagree		9	8.65	
Disagree		24	23.08	
	Not applicable	33	31.73	
	Agree	20	19.23	
	Neither agree nor disagree	13	12.5	
	Disagree	26	25.0	
	Not applicable	45	43.27	

Workplace experience among people in different age groups.

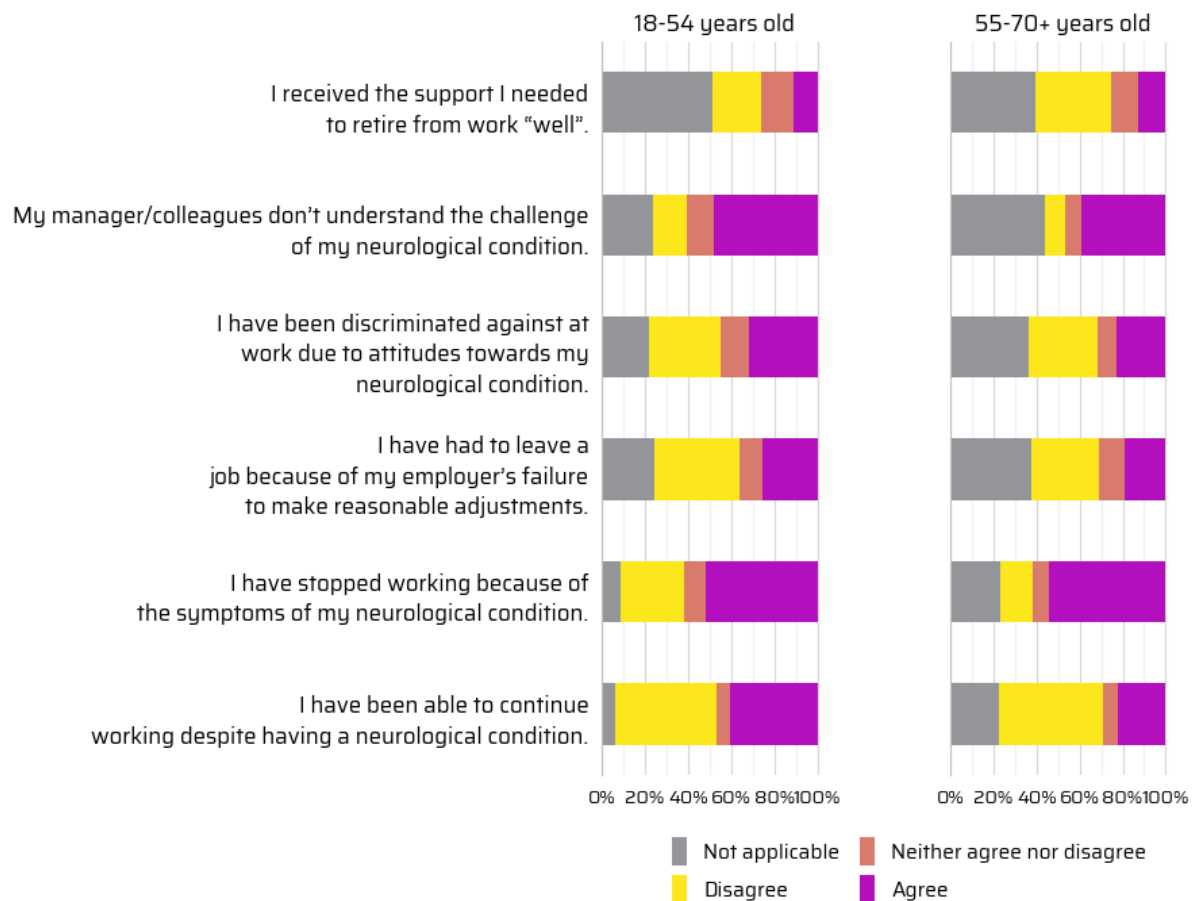


Figure 4 : Workplace experience among people in different age groups.

Table 4 : Workplace experience among people in different age groups.

Age	Workplace experience	Response	Respondents	Percentage
55-70+	I have been able to continue working despite having a neurological condition.	Agree	47	22.27
		Neither agree nor disagree	15	7.11
		Disagree	101	47.87
		Not applicable	48	22.75
	I have stopped working because of the symptoms of my neurological condition.	Agree	114	54.29
		Neither agree nor disagree	15	7.14
		Disagree	32	15.24
		Not applicable	49	23.33

	Agree	40	19.05
	Neither agree nor disagree	25	11.9
	Disagree	66	31.43
	Not applicable	79	37.62
I have had to leave a job because of my employer's failure to make reasonable adjustments.	Agree	49	23.11
	Neither agree nor disagree	18	8.49
	Disagree	68	32.08
	Not applicable	77	36.32
I have been discriminated against at work due to attitudes towards my neurological condition.	Agree	82	38.86
	Neither agree nor disagree	17	8.06
	Disagree	20	9.48
	Not applicable	92	43.6
My manager/colleagues don't understand the challenge of my neurological condition.	Agree	27	12.8
	Neither agree nor disagree	27	12.8
	Disagree	73	34.6
	Not applicable	84	39.81
I received the support I needed to retire from work "well".	Agree	65	40.62
	Neither agree nor disagree	10	6.25
	Disagree	75	46.88
	Not applicable	10	6.25
18-54	Agree	83	51.88
	Neither agree nor disagree	16	10.0
	Disagree	47	29.38
	Not applicable	14	8.75
I have stopped working because of the symptoms of my neurological condition.			

I have had to leave a job because of my employer's failure to make reasonable adjustments.	Agree	41	25.47
	Neither agree nor disagree	17	10.56
	Disagree	64	39.75
	Not applicable	39	24.22
I have been discriminated against at work due to attitudes towards my neurological condition.	Agree	51	31.68
	Neither agree nor disagree	21	13.04
	Disagree	54	33.54
	Not applicable	35	21.74
My manager/colleagues don't understand the challenge of my neurological condition.	Agree	77	48.12
	Neither agree nor disagree	20	12.5
	Disagree	25	15.62
	Not applicable	38	23.75
I received the support I needed to retire from work "well".	Agree	18	11.18
	Neither agree nor disagree	24	14.91
	Disagree	36	22.36
	Not applicable	83	51.55

Workplace experience among people of different genders.

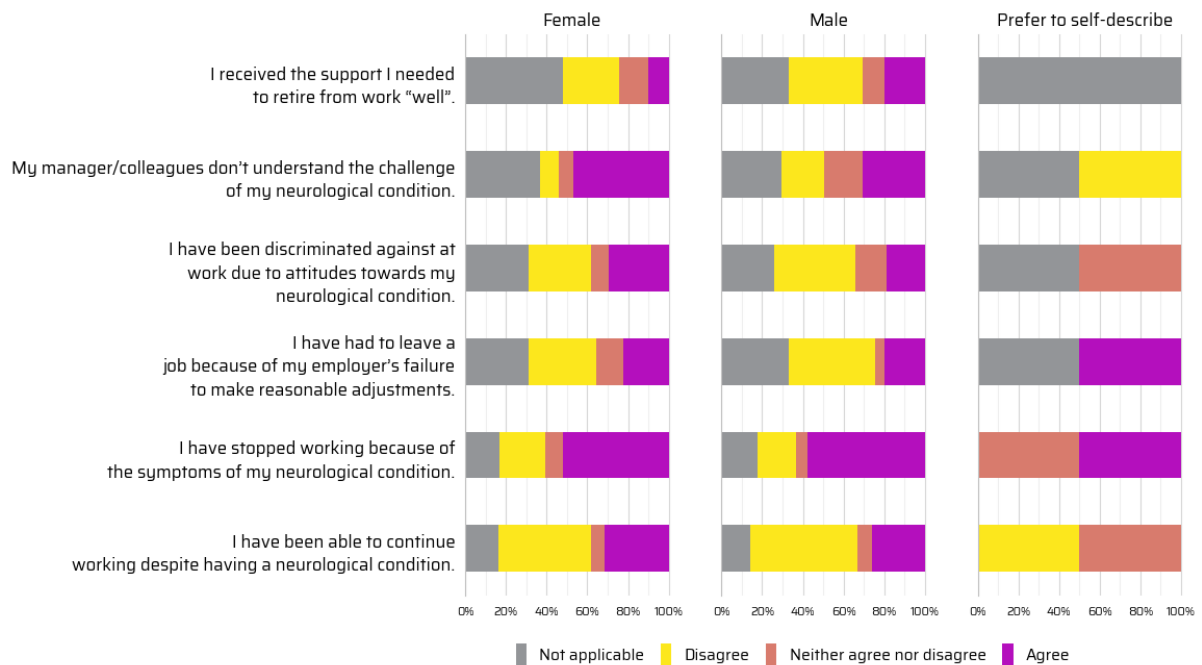


Figure 5 : Workplace experience among people of different genders.

Table 5 : Workplace experience among people of different genders.

Gender	Workplace experience	Response	Respondents	Percentage
Female	I have been able to continue working despite having a neurological condition.	Agree	90	31.69
		Neither agree nor disagree	18	6.34
		Disagree	130	45.77
		Not applicable	46	16.2
	I have stopped working because of the symptoms of my neurological condition.	Agree	147	51.94
		Neither agree nor disagree	25	8.83
		Disagree	63	22.26
		Not applicable	48	16.96
	I have had to leave a job because of my employer's failure to make reasonable adjustments.	Agree	63	22.18
		Neither agree nor disagree	38	13.38
		Disagree	94	33.1

		Not applicable	89	31.34
		Agree	84	29.37
	I have been discriminated against at work due to attitudes towards my neurological condition.	Neither agree nor disagree	25	8.74
		Disagree	88	30.77
		Not applicable	89	31.12
		Agree	133	46.83
	My manager/colleagues don't understand the challenge of my neurological condition.	Neither agree nor disagree	21	7.39
		Disagree	26	9.15
		Not applicable	104	36.62
		Agree	28	9.82
	I received the support I needed to retire from work "well".	Neither agree nor disagree	42	14.74
		Disagree	78	27.37
		Not applicable	137	48.07
		Agree	22	25.88
	I have been able to continue working despite having a neurological condition.	Neither agree nor disagree	6	7.06
		Disagree	45	52.94
		Not applicable	12	14.12
		Agree	49	57.65
Male	I have stopped working because of the symptoms of my neurological condition.	Neither agree nor disagree	5	5.88
		Disagree	16	18.82
		Not applicable	15	17.65
		Agree	17	20.0
	I have had to leave a job because of my employer's failure to make reasonable adjustments.	Neither agree nor disagree	4	4.71
		Disagree	36	42.35

		Not applicable	28	32.94
		Agree	16	18.82
	I have been discriminated against at work due to attitudes towards my neurological condition.	Neither agree nor disagree	13	15.29
		Disagree	34	40.0
		Not applicable	22	25.88
		Agree	26	30.59
	My manager/colleagues don't understand the challenge of my neurological condition.	Neither agree nor disagree	16	18.82
		Disagree	18	21.18
		Not applicable	25	29.41
		Agree	17	20.0
	I received the support I needed to retire from work "well".	Neither agree nor disagree	9	10.59
		Disagree	31	36.47
		Not applicable	28	32.94
		Agree	0	0.0
	I have been able to continue working despite having a neurological condition.	Neither agree nor disagree	1	50.0
		Disagree	1	50.0
		Not applicable	0	0.0
Prefer to self-describe		Agree	1	50.0
	I have stopped working because of the symptoms of my neurological condition.	Neither agree nor disagree	1	50.0
		Disagree	0	0.0
		Not applicable	0	0.0
		Agree	1	50.0
	I have had to leave a job because of my employer's failure to make reasonable adjustments.	Neither agree nor disagree	0	0.0
		Disagree	0	0.0
		Agree	1	50.0
		Neither agree nor disagree	0	0.0
		Disagree	0	0.0

	Not applicable	1	50.0
	Agree	0	0.0
I have been discriminated against at work due to attitudes towards my neurological condition.	Neither agree nor disagree	1	50.0
	Disagree	0	0.0
	Not applicable	1	50.0
	Agree	0	0.0
My manager/colleagues don't understand the challenge of my neurological condition.	Neither agree nor disagree	0	0.0
	Disagree	1	50.0
	Not applicable	1	50.0
	Agree	0	0.0
I received the support I needed to retire from work "well".	Neither agree nor disagree	0	0.0
	Disagree	0	0.0
	Not applicable	2	100.0

Workplace experience among people with different employment statuses.

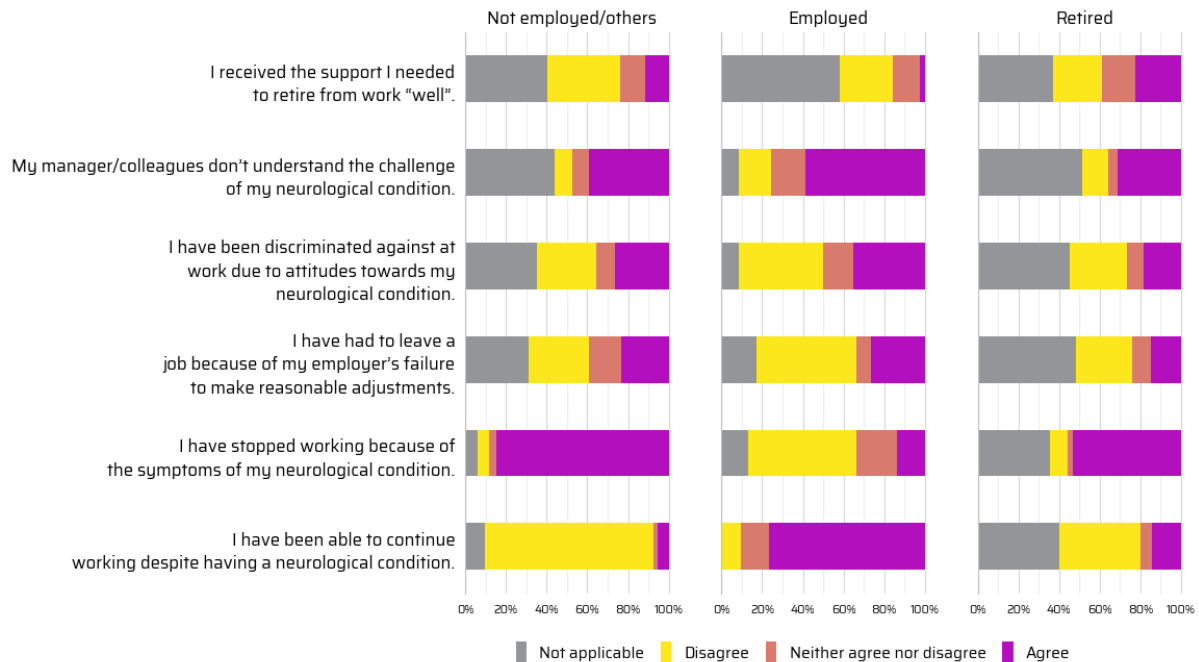


Figure 6 : Workplace experience among people with different employment statuses.

Table 6 : Workplace experience among people with different employment statuses.

Employment status	Workplace experience	Response	Respondents	Percentage
Not employed / others	I have been able to continue working despite having a neurological condition.	Agree	8	5.48
		Neither agree nor disagree	3	2.05
		Disagree	121	82.88
		Not applicable	14	9.59
	I have stopped working because of the symptoms of my neurological condition.	Agree	123	84.83
		Neither agree nor disagree	5	3.45
		Disagree	8	5.52
		Not applicable	9	6.21
	I have had to leave a job because of my employer's failure	Agree	34	23.13
		Neither agree nor disagree	24	16.33

	to make reasonable adjustments.	Disagree	43	29.25
		Not applicable	46	31.29
	I have been discriminated against at work due to attitudes towards my neurological condition.	Agree	39	26.53
		Neither agree nor disagree	13	8.84
		Disagree	43	29.25
		Not applicable	52	35.37
	My manager/colleagues don't understand the challenge of my neurological condition.	Agree	57	39.04
		Neither agree nor disagree	12	8.22
		Disagree	13	8.9
		Not applicable	64	43.84
	I received the support I needed to retire from work "well".	Agree	17	11.56
		Neither agree nor disagree	18	12.24
		Disagree	53	36.05
		Not applicable	59	40.14
	I have been able to continue working despite having a neurological condition.	Agree	88	76.52
		Neither agree nor disagree	16	13.91
		Disagree	11	9.57
		Not applicable	0	0.0
Employed	I have stopped working because of the symptoms of my neurological condition.	Agree	16	13.79
		Neither agree nor disagree	23	19.83
		Disagree	62	53.45
		Not applicable	15	12.93
	I have had to leave a job because of my employer's failure	Agree	31	26.72
		Neither agree nor disagree	8	6.9

	to make reasonable adjustments.	Disagree	57	49.14
		Not applicable	20	17.24
	I have been discriminated against at work due to attitudes towards my neurological condition.	Agree	41	35.34
		Neither agree nor disagree	17	14.66
		Disagree	48	41.38
		Not applicable	10	8.62
	My manager/colleagues don't understand the challenge of my neurological condition.	Agree	68	58.62
		Neither agree nor disagree	20	17.24
		Disagree	18	15.52
		Not applicable	10	8.62
	I received the support I needed to retire from work "well".	Agree	3	2.61
		Neither agree nor disagree	15	13.04
		Disagree	30	26.09
		Not applicable	67	58.26
	I have been able to continue working despite having a neurological condition.	Agree	16	14.55
		Neither agree nor disagree	6	5.45
		Disagree	44	40.0
		Not applicable	44	40.0
Retired	I have stopped working because of the symptoms of my neurological condition.	Agree	58	53.21
		Neither agree nor disagree	3	2.75
		Disagree	9	8.26
		Not applicable	39	35.78
	I have had to leave a job because of my employer's failure	Agree	16	14.81
		Neither agree nor disagree	10	9.26

to make reasonable adjustments.	Disagree	30	27.78
	Not applicable	52	48.15
I have been discriminated against at work due to attitudes towards my neurological condition.	Agree	20	18.18
	Neither agree nor disagree	9	8.18
	Disagree	31	28.18
	Not applicable	50	45.45
My manager/colleagues don't understand the challenge of my neurological condition.	Agree	34	31.19
	Neither agree nor disagree	5	4.59
	Disagree	14	12.84
	Not applicable	56	51.38
I received the support I needed to retire from work "well".	Agree	25	22.73
	Neither agree nor disagree	18	16.36
	Disagree	26	23.64
	Not applicable	41	37.27

Workplace experience among people with vs without dependents

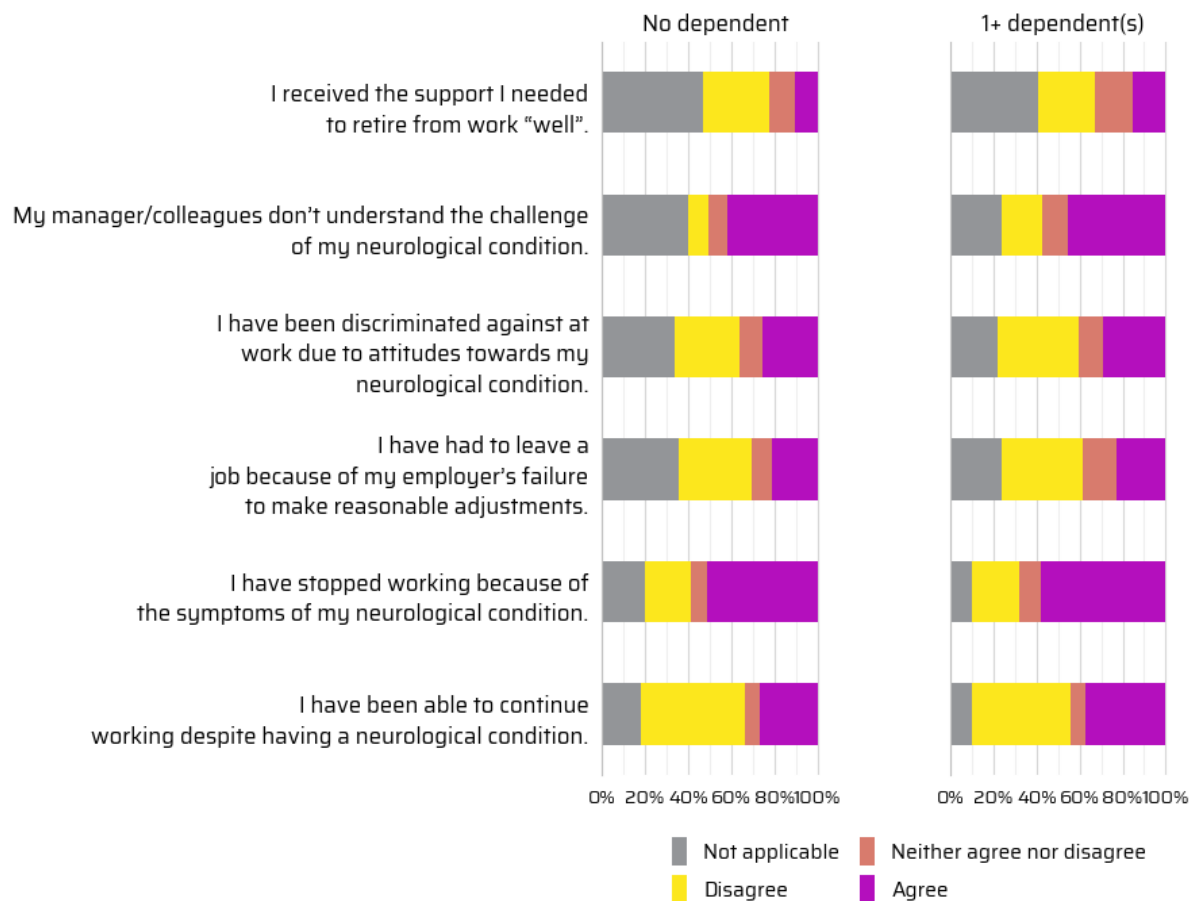


Figure 7: Workplace experience among people with vs without dependents.

Table 7: Workplace experience among people with vs without dependents.

Number of dependents	Workplace experience	Response	Respondents	Percentage
1+ dependent(s)	I have been able to continue working despite having a neurological condition.	Agree	43	37.07
		Neither agree nor disagree	8	6.9
		Disagree	53	45.69
		Not applicable	12	10.34
	I have stopped working because of the symptoms of my neurological condition.	Agree	67	57.76
		Neither agree nor disagree	12	10.34
		Disagree	25	21.55

	Not applicable	12	10.34
I have had to leave a job because of my employer's failure to make reasonable adjustments.	Agree	27	23.08
	Neither agree nor disagree	18	15.38
	Disagree	44	37.61
	Not applicable	28	23.93
I have been discriminated against at work due to attitudes towards my neurological condition.	Agree	34	29.06
	Neither agree nor disagree	13	11.11
	Disagree	44	37.61
	Not applicable	26	22.22
My manager/colleagues don't understand the challenge of my neurological condition.	Agree	53	45.3
	Neither agree nor disagree	14	11.97
	Disagree	22	18.8
	Not applicable	28	23.93
I received the support I needed to retire from work "well".	Agree	18	15.52
	Neither agree nor disagree	20	17.24
	Disagree	31	26.72
	Not applicable	47	40.52
No dependent	Agree	69	27.06
	Neither agree nor disagree	17	6.67
	Disagree	123	48.24
	Not applicable	46	18.04
I have stopped working because of the symptoms of my neurological condition.	Agree	130	51.18
	Neither agree nor disagree	19	7.48
	Disagree	54	21.26

	Not applicable	51	20.08
I have had to leave a job because of my employer's failure to make reasonable adjustments.	Agree	54	21.26
	Neither agree nor disagree	24	9.45
	Disagree	86	33.86
	Not applicable	90	35.43
I have been discriminated against at work due to attitudes towards my neurological condition.	Agree	66	25.78
	Neither agree nor disagree	26	10.16
	Disagree	78	30.47
	Not applicable	86	33.59
My manager/colleagues don't understand the challenge of my neurological condition.	Agree	106	41.73
	Neither agree nor disagree	23	9.06
	Disagree	23	9.06
	Not applicable	102	40.16
I received the support I needed to retire from work "well".	Agree	27	10.55
	Neither agree nor disagree	31	12.11
	Disagree	78	30.47
	Not applicable	120	46.88

Workplace experience dependent on extent mental health needs are being met.

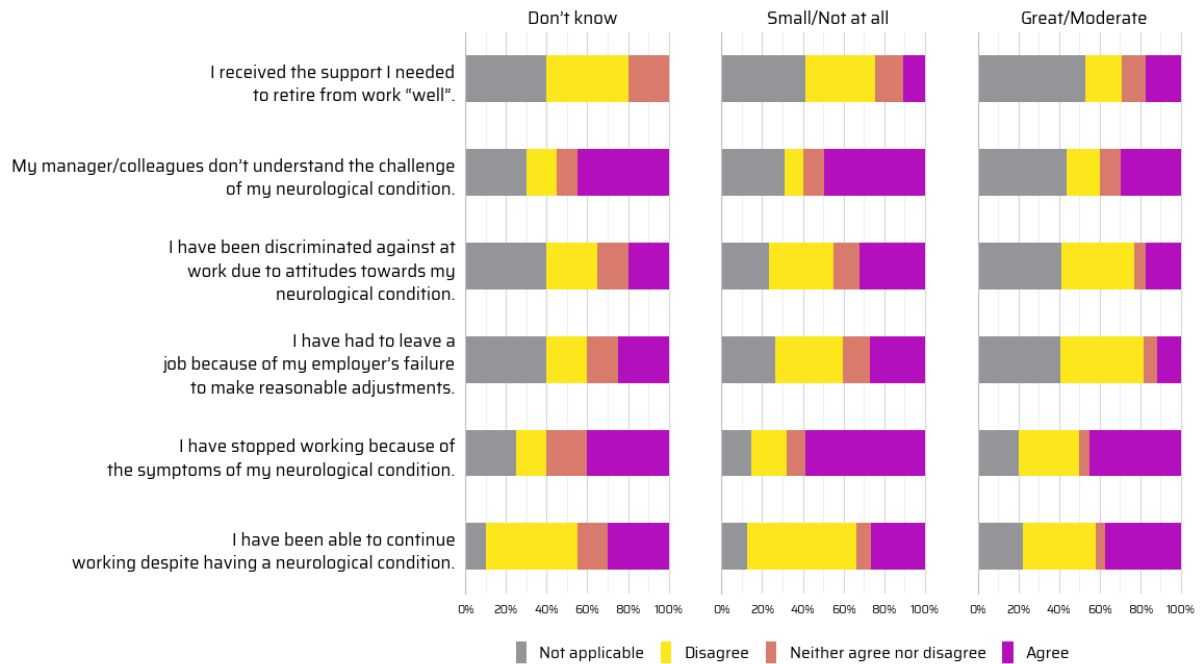


Figure 8 : Workplace experience dependent on extent mental health needs are being met.

Table 8 : Workplace experience dependent on extent mental health needs are being met.

Needs met	Workplace experience	Response	Respondents	Percentage
Great/Moderate	I have been able to continue working despite having a neurological condition.	Agree	61	26.52
		Neither agree nor disagree	16	6.96
		Disagree	124	53.91
		Not applicable	29	12.61
Small/Not at all	I have stopped working because of the symptoms of my neurological condition.	Agree	135	58.7
		Neither agree nor disagree	21	9.13
		Disagree	40	17.39
		Not applicable	34	14.78
Don't know	I have had to leave a job because of my employer's failure	Agree	62	26.96
		Neither agree nor disagree	31	13.48

	to make reasonable adjustments.	Disagree	76	33.04
		Not applicable	61	26.52
	I have been discriminated against at work due to attitudes towards my neurological condition.	Agree	75	32.33
		Neither agree nor disagree	29	12.5
		Disagree	74	31.9
		Not applicable	54	23.28
	My manager/colleagues don't understand the challenge of my neurological condition.	Agree	114	49.57
		Neither agree nor disagree	23	10.0
		Disagree	22	9.57
		Not applicable	71	30.87
	I received the support I needed to retire from work "well".	Agree	24	10.39
		Neither agree nor disagree	33	14.29
		Disagree	79	34.2
		Not applicable	95	41.13
	I have been able to continue working despite having a neurological condition.	Agree	45	37.19
		Neither agree nor disagree	6	4.96
		Disagree	43	35.54
		Not applicable	27	22.31
Great/Moderate	I have stopped working because of the symptoms of my neurological condition.	Agree	54	45.0
		Neither agree nor disagree	6	5.0
		Disagree	36	30.0
		Not applicable	24	20.0
	I have had to leave a job because of my employer's failure	Agree	14	11.57
		Neither agree nor disagree	8	6.61

	to make reasonable adjustments.	Disagree	50	41.32
		Not applicable	49	40.5
	I have been discriminated against at work due to attitudes towards my neurological condition.	Agree	21	17.36
		Neither agree nor disagree	7	5.79
		Disagree	43	35.54
		Not applicable	50	41.32
	My manager/colleagues don't understand the challenge of my neurological condition.	Agree	36	29.75
		Neither agree nor disagree	12	9.92
		Disagree	20	16.53
		Not applicable	53	43.8
	I received the support I needed to retire from work "well".	Agree	21	17.36
		Neither agree nor disagree	14	11.57
		Disagree	22	18.18
		Not applicable	64	52.89
	I have been able to continue working despite having a neurological condition.	Agree	6	30.0
		Neither agree nor disagree	3	15.0
		Disagree	9	45.0
		Not applicable	2	10.0
Don't know	I have stopped working because of the symptoms of my neurological condition.	Agree	8	40.0
		Neither agree nor disagree	4	20.0
		Disagree	3	15.0
		Not applicable	5	25.0
	I have had to leave a job because of my employer's failure	Agree	5	25.0
		Neither agree nor disagree	3	15.0

to make reasonable adjustments.	Disagree	4	20.0
	Not applicable	8	40.0
I have been discriminated against at work due to attitudes towards my neurological condition.	Agree	4	20.0
	Neither agree nor disagree	3	15.0
	Disagree	5	25.0
	Not applicable	8	40.0
My manager/colleagues don't understand the challenge of my neurological condition.	Agree	9	45.0
	Neither agree nor disagree	2	10.0
	Disagree	3	15.0
	Not applicable	6	30.0
I received the support I needed to retire from work "well".	Agree	0	0.0
	Neither agree nor disagree	4	20.0
	Disagree	8	40.0
	Not applicable	8	40.0

The impact of neurological conditions on employment

The respondents were asked to describe the impacts of their neurological conditions on their employment. A word cloud is generated for the responses.

Word cloud

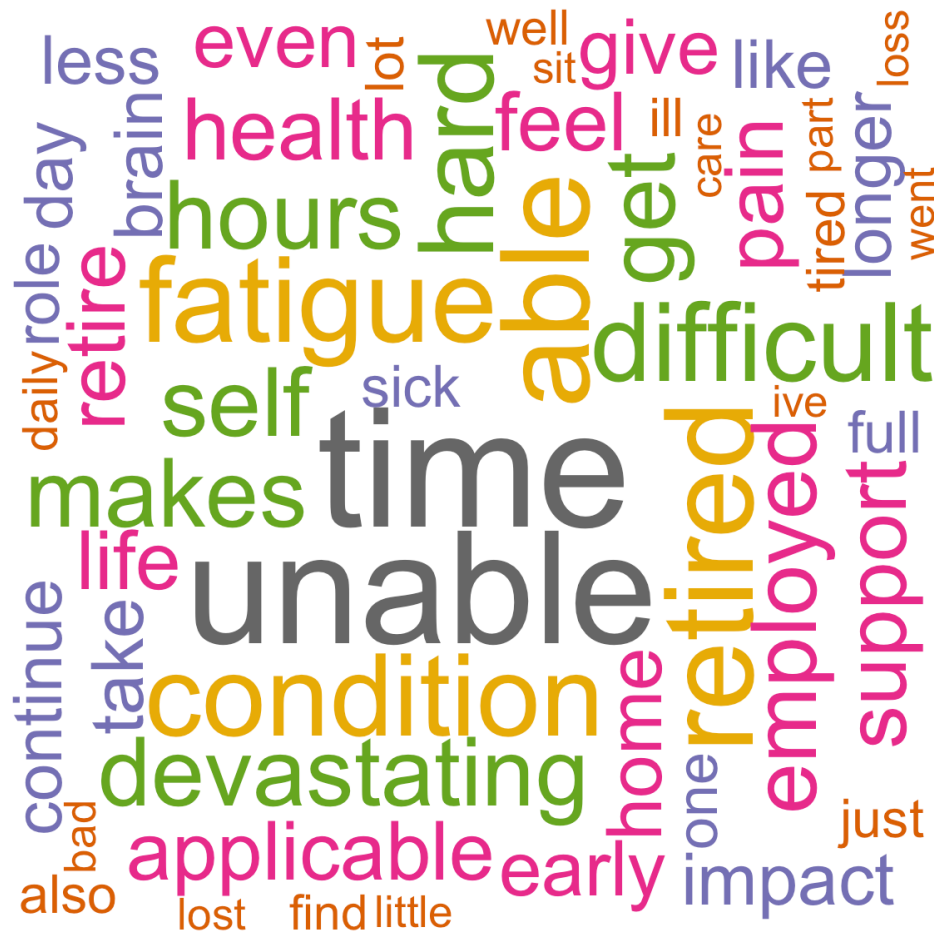


Figure 9 : Word cloud showing key words used by respondents related to impacts of neurological conditions on employment.

Thematic analysis

A thematic analysis was conducted for responses to the question. Overall, the following 5 themes with their sub-themes emerged:

- **Theme 1: Changes in employment status.**
 - Switched jobs or job mode.
 - Unable to continue working/retired early.
 - Lost jobs/laid off.
 - Not able to gain employment.
- **Theme 2: Impact on ability to work.**
 - Physical ability to work.
 - Absence at work.

- Career advancement was held back.
- Overcompensate by working harder.
- **Theme 3: Impact on mental health**
 - Loss of identity.
 - Impact on self-esteem.
 - Emotional distress.
- **Theme 4: Lack of support from workplace**
 - Lack of understanding.
 - Unsupportive employers and colleagues.
 - No adjustments made/accessibility issues.
 - Did not tell employer.
- **Theme 5: Little to no impact**

Theme 1: Changes in employment status

Switched jobs or job mode

Some respondents had to switch their jobs or job modes, such as going part-time, becoming self-employed, working with reduced hours, or working from home. Overall, adjustments to their employment had been made for their neurological conditions.

“I have needed to change careers as I was physically unable to perform.”

“I have had to go to part time hours but my work place have been very understanding.

“Have had to go self employed.”

“Dropping hours in Sept on advice of doctor.”

“Able to work from home but not able to go to the office.”

Unable to continue working/retired early.

Some respondents were unable to continue working and had to stop working. They retired early or were medically retired.

“Had to stop working when I could no longer walk and needed to use a wheelchair.”

“As I became more systematic, particularly my ability to mobilise less than 200 metres, I had to retire as my job was based outside in the community where my job was based.”

“Despite reasonable adjustments efforts, it reached a point at which I could not satisfy the requirements of my employment and I was medically retired to due to serious ill health.....This was subsequently confirmed by HMRC medical advisor who stipulated that I was to be medically retired under the severe ill health medical retirement rules.”

Lost jobs/laid off.

There were also respondents who had their jobs terminated by their employers due to their neurological conditions.

“I was forced into redundancy I had no choice but to leave my job I loved and it’s taken away the last little bit of hope I had.”

“It ended it all, my original career and my second career.

“I was dismissed after 2 years, 1 year with no pay.”

“I was offered a settlement agreement by my employer shortly after receiving my diagnosis - although I was not fully informed about any aspect of my condition or the impact it would have on me at the time - so I was unaware of my disability status and the legal rights covering my employment. Therefore, I accepted a much lower settlement offer than I could have received had I been properly informed by my original consultant at the time.”

Not able to gain employment.

It was also reported that respondents could not regain employment after having neurological conditions.

“Impossible to gain any employment or volunteering role, due to everyone not understanding or being constantly too frightened of my disability.”

“I have tried to find other work but because of my conditions I've not been successful.”

Theme 2: Impact on ability to work.

Physical ability to work.

It was reported that having neurological conditions have impacted respondents' physical ability to work, with difficulties related to mobility, spatial awareness, concentration, fatigue, memory issues, using computers, and loud noises.

“My job involved a lot of walking, climbing equipment & driving forktrucks. Being in pain walking & spasms, twisting of foot my doing any of that impossible.”

“I became unsafe and a liability with my reduced mobility but particularly with my spacial awareness impacting on moving through the sites or up or down shafts by means of ladders.”

“Fatigue, cognitive function impaired.”

“I suffer with neurological fatigue resulting in lack of concentration, focus and memory.”

” This affected my memory, concentration, increased fatigue.”

“Looking at a PC screen difficult with headaches and posture.”

“Loud noises can cause headaches and can’t do some action songs if my head is upside down! I teach in Early Years!”

Absence at work

The respondents' neurological conditions had also impacted their presence at work. They had to call in sick or take time off, such as taking disability leave.

"Before diagnosis I had to take lengthy time off work sick as I could not do my job due to severe pain and health and safety."

"I have to take frequent leave. Which is classed as disability leave. This is dealt with differently from general sickness leave."

"When my RLS is bad and I've not slept I can't function so have to have days off sick."

Career advancement was held back.

For some, their career advancement was held back as they had to skip promotion, or regain qualifications required for work after their recovery.

"Holds me back, skipped for recognition or promotion."

"It has restricted my progress."

"...even though I'm medically fit to drive there are huge back logs with the DVLA to process my application (apparently 12months plus)."

Overcompensate by working harder.

For some, they had to work harder and for longer hours compared to their colleagues to complete their work.

"Overcompensate by working harder than colleagues"

"It took me twice as long as others to complete a task but I carried out that task as well, if not better, than others. In order to complete work I would work through my lunchtime and unpaid overtime. I would often take work home in order to complete it."

"It takes me longer to do anything and I have to double check my work."

Theme 3: Impact on mental health

Loss of identity

One of the impacts on mental health related to losing their jobs is losing their identity. Respondents reported that their jobs were a major part of their life and losing them was disheartening.

"I was very disheartened especially as my senior role in the hospitality industry was a major part of my life."

"It has affected how I see myself. My role, my loss of self and independence."

Impact on self-esteem

Some respondents also reported impacts on self-esteem pertaining to how they were treated by their employer due to their neurological conditions.

“I had to give up my employment and no one helped with my symptoms which led to a long history of decline in my self esteem.”

“...rather than support me, my employer stated I was hesitant to answer questions about my condition. I was made to feel stupid.....It has had a massive impact on my confidence.”

“My confidence was destroyed by how I was treated by my employer.”

Emotional distress

Emotional distress emerged as a sub-theme in regard to impact on mental health related to how having neurological conditions may affect their employment.

“Terrible and the support I needed wasn’t given due to lack of understanding i felt like I was drowning.”

“It’s hard. Really hard. I’ve gone from being on top of my game to what feels like the bottom of the pile and it’s heartbreaking.”

“I cannot financially survive on benefits and pay for the costs associated with being unwell as well as paying for care. I try to remain positive but it’s a very bleak and isolating existence.”

Theme 4: Lack of support from workplace

Lack of understanding

It was reported that there is a lack of understanding at the workplace on the respondents’ situations.

“I don’t think there are many employers out there that understand my need to have a 3-4 hour sleep during the day to make it through the day, even if I have engaged only in minimal activity”

“It’s so hard to explain to colleagues that for me to walk somewhere else in the building is like them running a marathon. People also struggle to understand the variability of my condition or how getting a cold affects me compared to them.”

Unsupportive employers and colleagues

There were also unsupportive employers and colleagues.

“I was bullied out of every single work job I ever had, purely because all colleagues could never be bothered to assist me during any of my lifelong fully uncontrollable epilepsy seizures.”

“When I pointed this out to my manager, she said “well its up to you to come to me with a plan for how you would successfully take up the role and carry out all the required tasks! In effect I was managed out of the business due to my illness.”

No adjustments made/accessibility issues.

Some employers also refused to make reasonable adjustments for the respondents.

“My employer...decided to terminate my contract without any severance pay, due to their decision that I was unfit to undertake any of my former duties and there would be too many adjustments needed to accommodate me...”

“Refusal by employers to make reasonable adjustments required by law.”

Did not tell employer.

Some respondents decided not to disclose their conditions to their employers.

“I hid it from employers.”

“I didn’t disclose my diagnosis until it affected me physically.”

Theme 5: Little to no impact

Despite the 4 themes presented above, some respondents have also reported that their neurological conditions had little to no impact on their employment.

“I am self-employed and have been able to work as normal.”

“Did not impact on my employment.”

“Not applicable to me as I was self-employed.”

Workplace inclusivity

The respondents were asked how an employer and workplace could show they are inclusive of people affected by neurological conditions. A word cloud is generated for their responses.

Theme 1: Inclusive hiring process.

Respondents suggested that employers should be non-discriminating and transparent during the hiring process. Ideally, they should state in the job advertisement that they are an inclusive workplace.

“When recruiting state that they are inclusive and provide an accessible and supportive work place”

“During the recruitment process it would be helpful for employers to demonstrate awareness of health conditions (not just neurological) and give example of how they might make adjustments so that potential employees aren't afraid to ask.”

“Put on their job advert that they are inclusive, and will make any adjustments needed.”

“Celebrate diversity. Be transparent on the support and adjustments they can offer.”

Theme 2: Improve understanding on neurological conditions.

Educate themselves.

Employers should educate themselves about neurological conditions to improve their understanding.

“Should be willing to be educated more on how to deal with various types of illnesses / health problems.”

“Get themselves educated on how to treat those affected and work towards solutions”

“More understanding of these conditions my manager googled RLS and was shocked she she said. Then understood why I couldn't work when I'd had not slept.”

Ask and listen.

Another way for employers to improve their understanding on neurological conditions is to ask and listen to their employees with neurological conditions.

“Just by asking how to support me and try to accommodate adaptations”

“Take time to actually listen to those with the condition so that they can understand the challenges faced.”

“Ask what support people need & listen to them”

Staff awareness training

Some respondents also suggested that it is important to raise awareness and understanding about neurological conditions in workplaces, which can be implemented by providing awareness training.

“Training for managers...”

“raising greater awareness of people with neurological symptoms and ensuring that there is a supportive atmosphere especially amongst colleagues and management”

“if necessary training for other staff”

“I didn't talk much about reason for poor memory, I took lots of notes, my boss joked about my notebooks, if there was online resources that employees could bring to the attention of their employers if would be great.”

“Have more general awareness and to create an environment where individuals feel able and comfortable to share their experience and the impact of this. Create better awareness that not all conditions are visible.”

Show understanding, compassion, and acknowledgement.

It is also important to show understanding, support and acceptance towards employees with neurological conditions. Employers should acknowledge the hard work and impact of people's conditions.

“An understanding HR department that understood that folk like us may need extra time off for appointments etc, without penalty.”

“They need to be active in their support rather than segregate people with neurological conditions.”

“Recognise our bravery and commitment.”

“show compassion - I never let them down, worked hard but struggled with numbers affecting my work”

“If the workplace was more 'forgiving' and suited to employees with brain injuries there is more scope for employer understanding.”

Research

Employers are also urged to conduct more research to understand how to make their workplaces more inclusive, such as by forming focus groups and reaching out to charities.

“Research, ask questions, form a focus group, speak to charities. Invite open communication.”

“Greater understanding and willingness to research and adapt workplace surroundings in order to retain employees that often have a longstanding wealth of knowledge and experience”

“By actively belonging to organisations such as this. That will give them the insight into what changes they may have to make to their business.”

Theme 3: Offer support proactively

Make reasonable adjustments

It was suggested that employers should offer support proactively by making reasonable adjustments for employees with neurological conditions. This includes providing specialist

provisions, occupational health, disable-friendly facilities (wheelchair access, disabled toilet, and automatic door), quiet space, and disabled parking spaces.

“By providing specialist provisions for those who need them.”

“A properly staffed occupational health department and a bigger budget.”

“Provide wheelchair access and disabled toilet as minimum and compulsory.”

“...wouldn't put an automatic door in so I could access my work department as only I would need to use it. But in reality, it would have benefitted so many other people at the time and potentially in the future.”

“Arrange parking spaces at work and a 'quiet room' for sleep/rest.”

“provide easier access to parking”

“physically things that could help like certain chairs and heights ,positioning of work space ,orientation etc .”

“Allow employees "recovery time" e.g. if they had to engage in anything that was physically draining”

“Some basics could include level access, hand rails even on flat corridors, disabled toilets with alarm cords....”

Support group/disability network

It was also mentioned that support group or disability network should be formed.

“start support group”

“Having a disability network....”

Supplementary support e.g., Insurance claims

There are also other form of supplementary support that employers can offer, such as helping with insurance claims.

“Having...disability passports”

“Assisting with insurance claims”

Regular check-ins

Having regular check-ins with the employees with neurological conditions is also seen as a way to make the workplace more inclusive.

“Regular assessments as neurological conditions change frequently and this would help both the employer and me living with a neurological condition adapt where necessary.”

“Asking what support is needed and having regular follow ups to ensure they continue to feel supported in work.”

“Weekly chat discussing the week”

Legislation and policies

Having protective legislation and implementing inclusive policies were also cited as another way to ensure workplaces are more inclusive.

“The person with the neurological condition should raise the subject with his/her immediate manager sooner, not later. It would be up to the employee to explain to the best of their ability how the condition might affect their work, and when extra help is likely to be needed. Ideally the workplace would already have policies in place to deal with situations like this, and they should do everything possible to enable their employee to continue to work as normal.”

“By properly implementing their inclusion and diversity rules and not just playing lip service to them.”

“Legislation”

“By example & by having policies in place to guide provision of suitable adjustments and support.”

Theme 4: Flexible working

It was reported that employers should offer more options for flexible working to make their workplaces more inclusive for individuals with neurological conditions. This includes option to work with reduced hours, part-time, flexitime, having time-out, having disability leave, option to work from home, and option to consider an alternative role.

“Allow flexi-time/reduced hours/ permission for “time-out” during working hours to rest and recuperate.”

“Having disability passports and disability leave for those days you are sick because of your condition. So this is dealt with differently to ordinary sicknesses.”

“they could have created a split role both part time that would have meant I completed only office duties and the other person completed the flying duties.”

“Allowing working from home when unable to get into the office etc.”

“Completing required hours per week but working flexi-time.”

“Help to find an alternative role.”

“by allowing time off for medical appointments.”

“Allowing remote part time and if we are having spasms or flare up allow us time to recover.”

Theme 5: No “one size fits all” solution

Some respondents have acknowledge that neurological conditions are complex and there is no “one size fits all” solution.

“Neurological conditions are so varied and people with them have such differing needs that I don't think there is a single "one size fits all" answer to this. I would suggest that employers should be talking to all their staff and asking what would help them”

“It would help if they were more open to acknowledging differences. Management training seems to instil a one-size-fits-all approach instead of one that encourages managers to be sensitive to differences between people.”

“There is no blanket solution it would have to be job to job and condition to condition”

“Understand & listen to the symptoms & how it effect you each person is different”

Meeting specialists

Purpose of seeing or speaking to a specialist

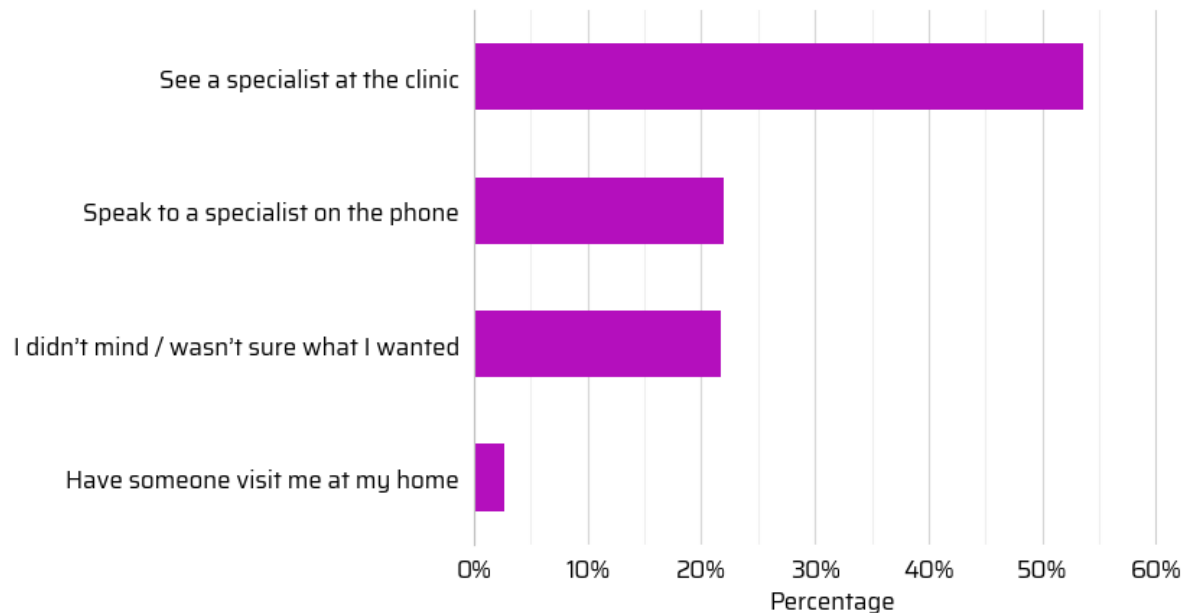


Figure 11 : Purpose of seeing or speaking to a specialist.

Table 9 : Purpose of seeing or speaking to a specialist.

Intention	Respondents	Percentage
See a specialist at the clinic	200	53.62
Speak to a specialist on the phone	82	21.98
I didn't mind / wasn't sure what I wanted	81	21.72
Have someone visit me at my home	10	2.68

Able to meet/speak to a specialist

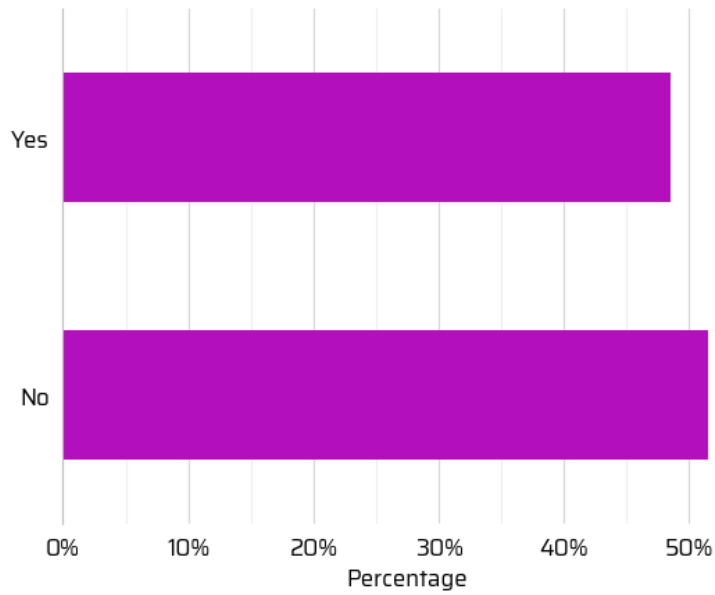


Figure 12 : Whether respondents were able to meet or speak to a specialist.

Table 10 : Whether respondents were able to meet or speak to a specialist.

Appointments	Respondents	Percentage
Yes	181	48.53
No	192	51.47

Convenience of meeting a specialist

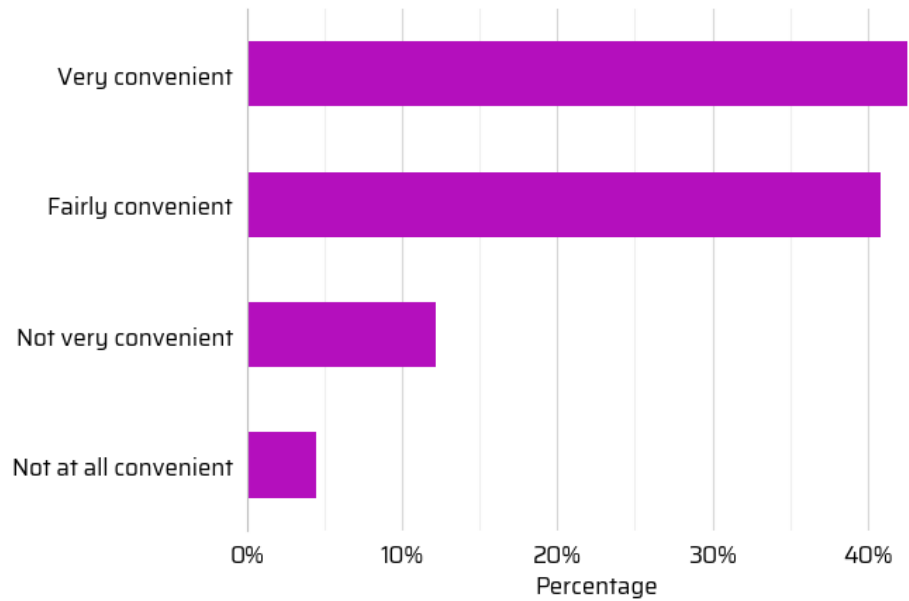


Figure 13 : Convenience of meeting a specialist.

Table 11 : Convenience of meeting a specialist.

Convenience	Respondents	Percentage
Very convenient	77	42.54
Fairly convenient	74	40.88
Not very convenient	22	12.15
Not at all convenient	8	4.42

Reasons of not getting an appointment or a convenient one

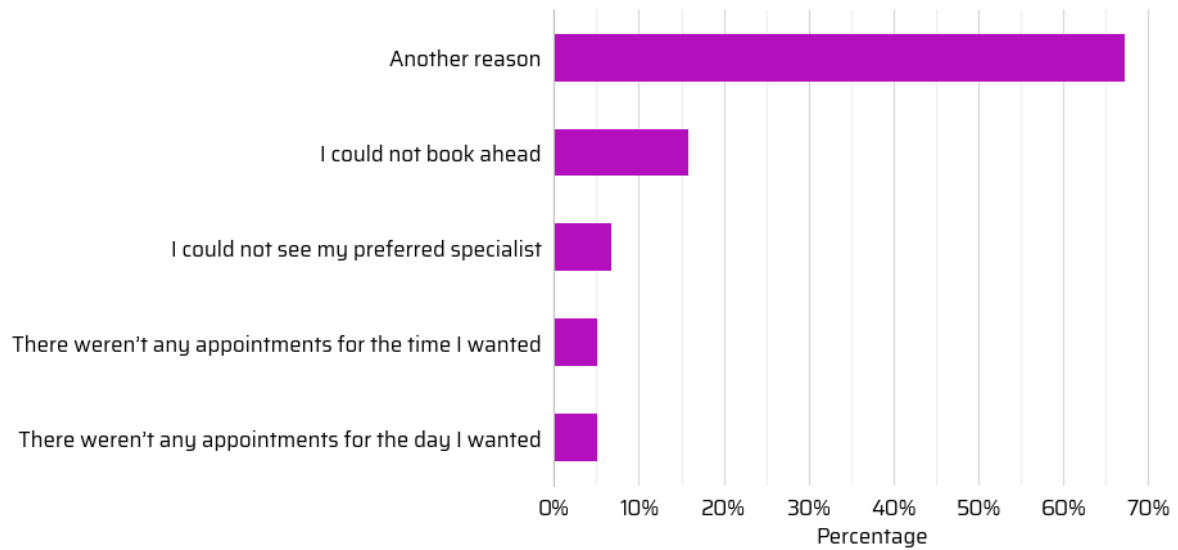


Figure 14 : Reasons of not getting an appointment or a convenient one.

Table 12 : Reasons of not getting an appointment or a convenient one.

Reason	Respondents	Percentage
Another reason	251	67.29
I could not book ahead	59	15.82
I could not see my preferred specialist	25	6.7
There weren't any appointments for the day I wanted	19	5.09
There weren't any appointments for the time I wanted	19	5.09

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

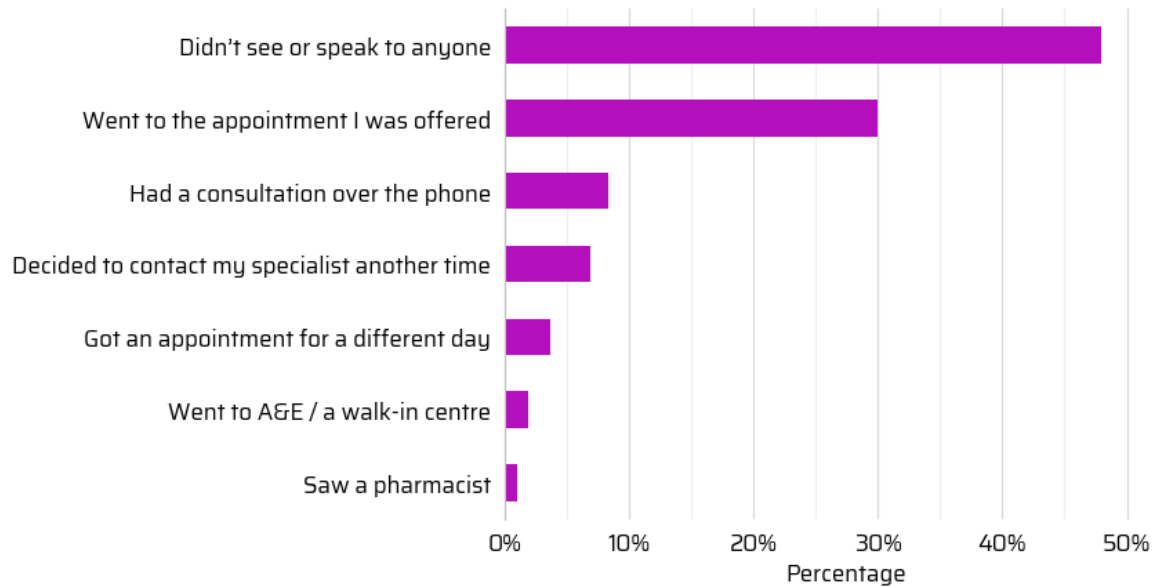


Figure 15 : Action taken following not getting an appointment/not offered a convenient one.

Table 13 : Action taken following not getting an appointment/not offered a convenient one.

Action	Respondents	Percentage
Didn't see or speak to anyone	179	47.99
Went to the appointment I was offered	112	30.03
Had a consultation over the phone	31	8.31
Decided to contact my specialist another time	26	6.97
Got an appointment for a different day	14	3.75
Went to A&E / a walk-in centre	7	1.88
Saw a pharmacist	4	1.07

Medical appointments

Access to medical appointments in the last eight weeks

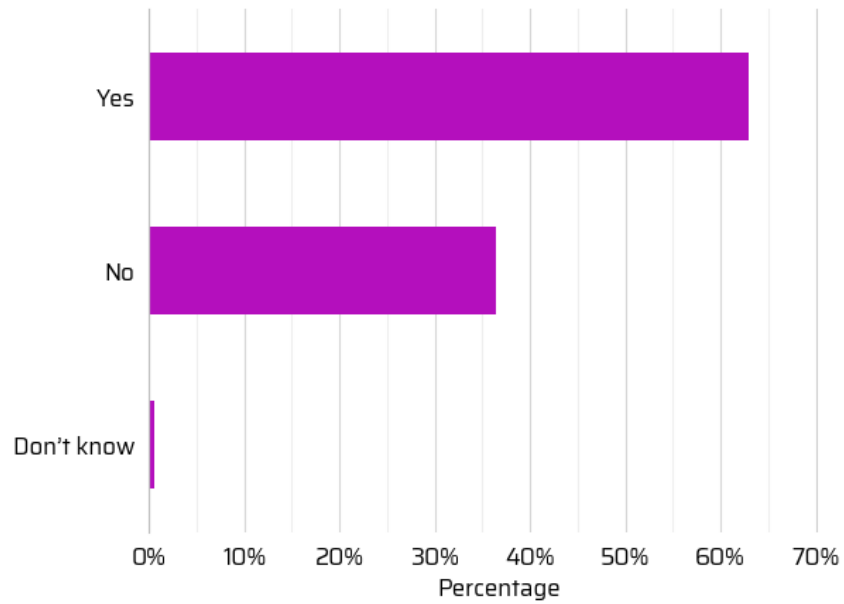


Figure 16 : Access to medical appointments in the last eight weeks.

Table 14 : Access to medical appointments in the last eight weeks.

Appointments	Respondents	Percentage
Yes	235	63.0
No	136	36.46
Don't know	2	0.54

Number of medical appointments

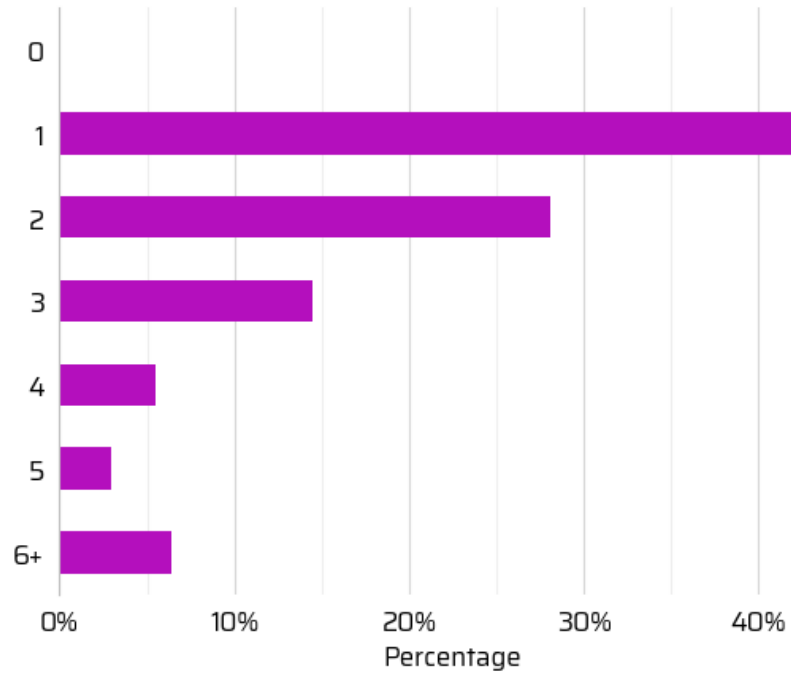


Figure 17 : Number of medical appointments.

Table 15 : Number of medical appointments.

Number of appointments	Respondents	Percentage
0	0	0.0
1	100	42.55
2	66	28.09
3	34	14.47
4	13	5.53
5	7	2.98
6+	15	6.38

Helpfulness of medical appointments

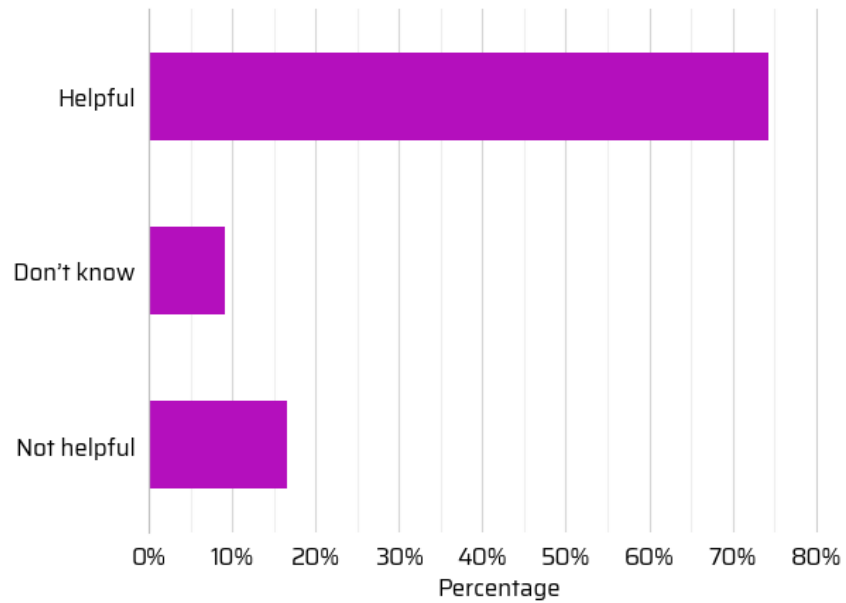


Figure 18 : Helpfulness of medical appointments held in the last eight weeks.

Table 16 : Helpfulness of medical appointments held in the last eight weeks.

Helpfulness	Respondents	Percentage
Helpful	277	74.26
Don't know	34	9.12
Not helpful	62	16.62

Specialty of medical appointments

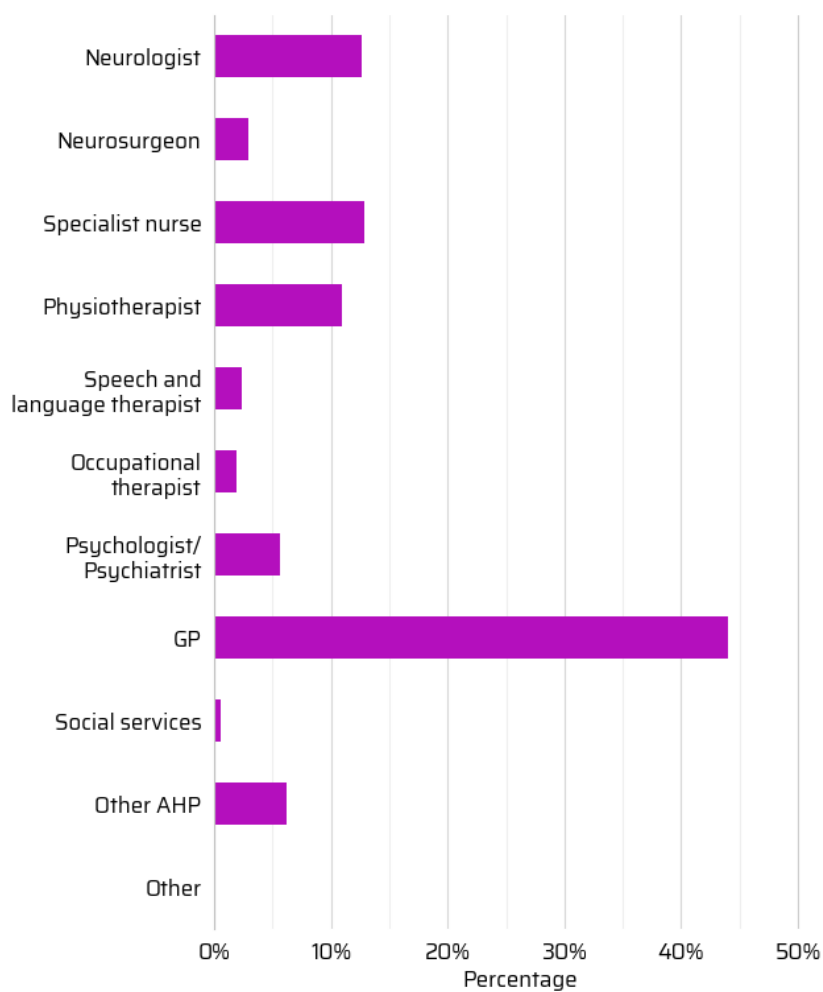


Figure 19 : Speciality of the medical appointments held in the last eight weeks.

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

Specialty	Respondents	Percentage
Neurologist	47	12.6
Neurosurgeon	11	2.95
Specialist nurse	48	12.87
Physiotherapist	41	10.99
Speech and language therapist	9	2.41
Occupational therapist	7	1.88
Psychologist / Psychiatrist	21	5.63
GP	164	43.97

Social services	2	0.54
Other AHP	23	6.17
Other	0	0.0

Mode of medical appointments completed.

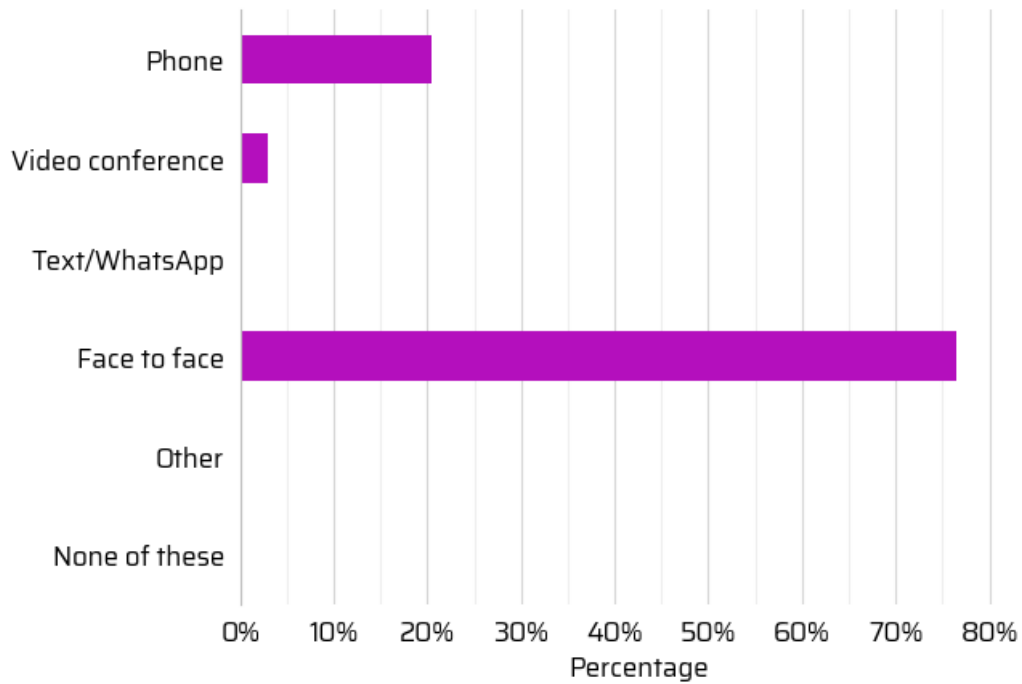


Figure 20 : Mode of medical appointments completed in the last eight weeks.

Table 18 : Mode of medical appointments completed in the last eight weeks.

Mode	Respondents	Percentage
Phone	76	20.38
Video conference	11	2.95
Text/WhatsApp	1	0.27
Face to face	285	76.41
Other	0	0.0
None of these	0	0.0

Mental health

Current feelings

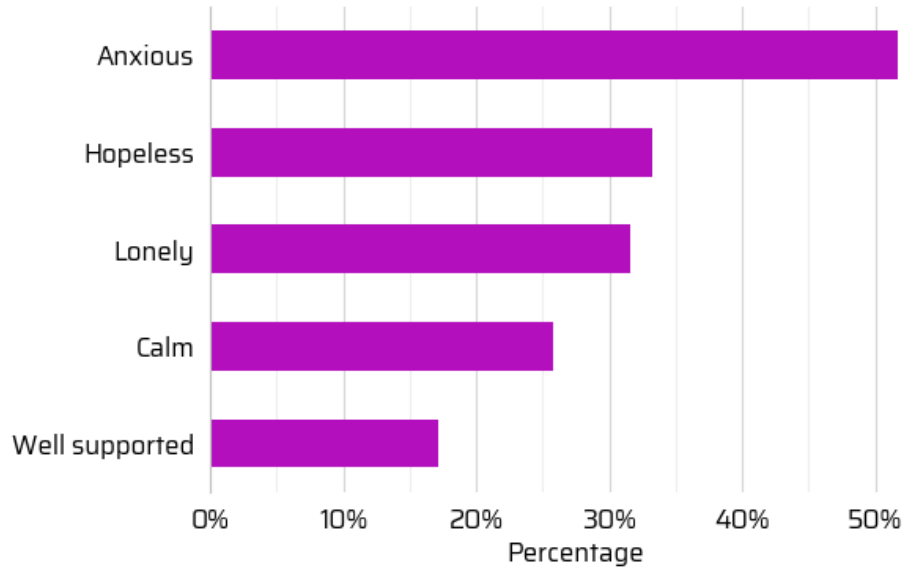


Figure 21 : Feelings of the respondents at the time of the survey.

Table 19 : Feelings of the respondents at the time of the survey.

Feelings	Respondents	Percentage
Well supported	64	17.16
Calm	96	25.74
Lonely	118	31.64
Hopeless	124	33.24
Anxious	193	51.74

Extent mental health needs are met

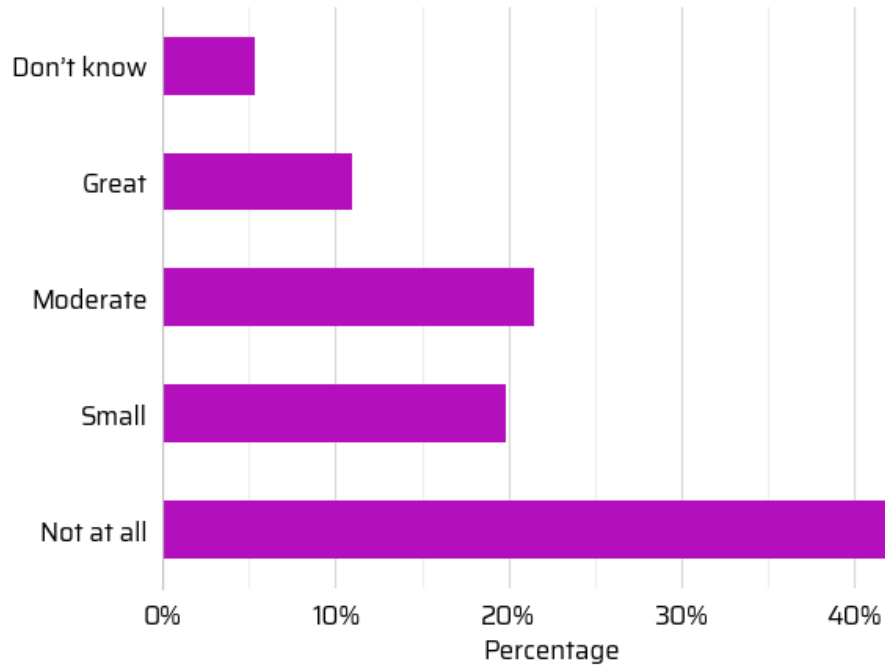


Figure 22 : Extent respondents reported their mental health needs were being met.

Table 20 : Extent respondents reported their mental health needs were being met.

Needs met	Respondents	Percentage
Don't know	20	5.36
Great	41	10.99
Moderate	80	21.45
Small	74	19.84
Not at all	158	42.36

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

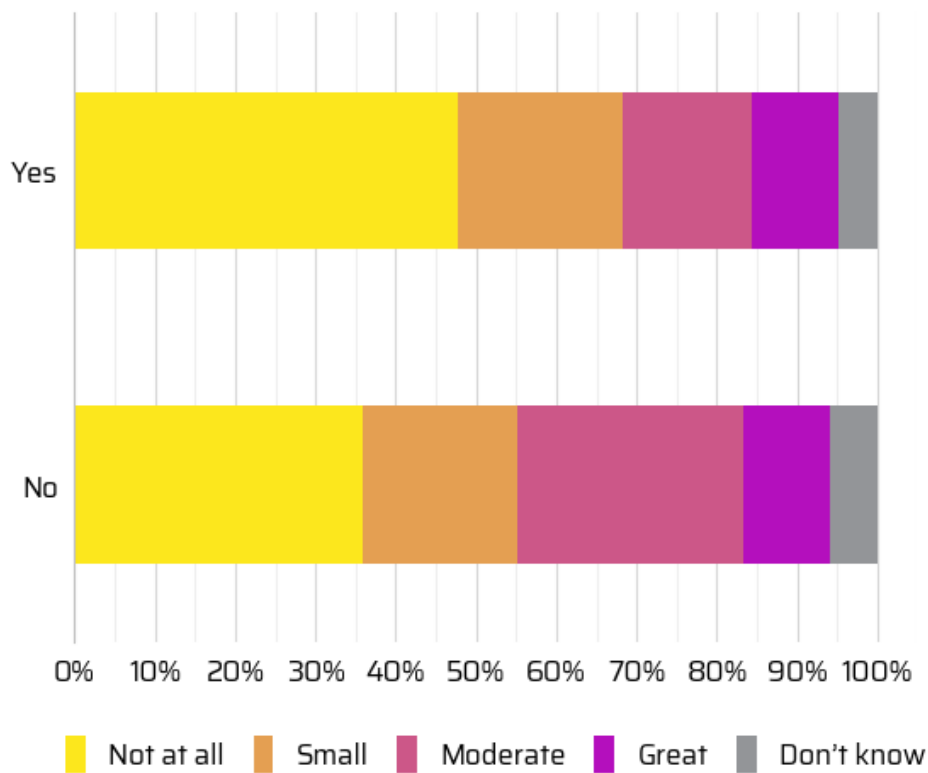


Figure 23 : Extent respondents reported their mental health needs were being met, broken down by whether diagnosed with multiple neurological conditions.

Table 21 : 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	10	4.88
	Great	22	10.73
	Moderate	33	16.1
	Small	42	20.49
	Not at all	98	47.8
No	Don't know	10	5.99
	Great	18	10.78

Moderate	47	28.14
Small	32	19.16
Not at all	60	35.93

Extent mental health needs are met by age groups.

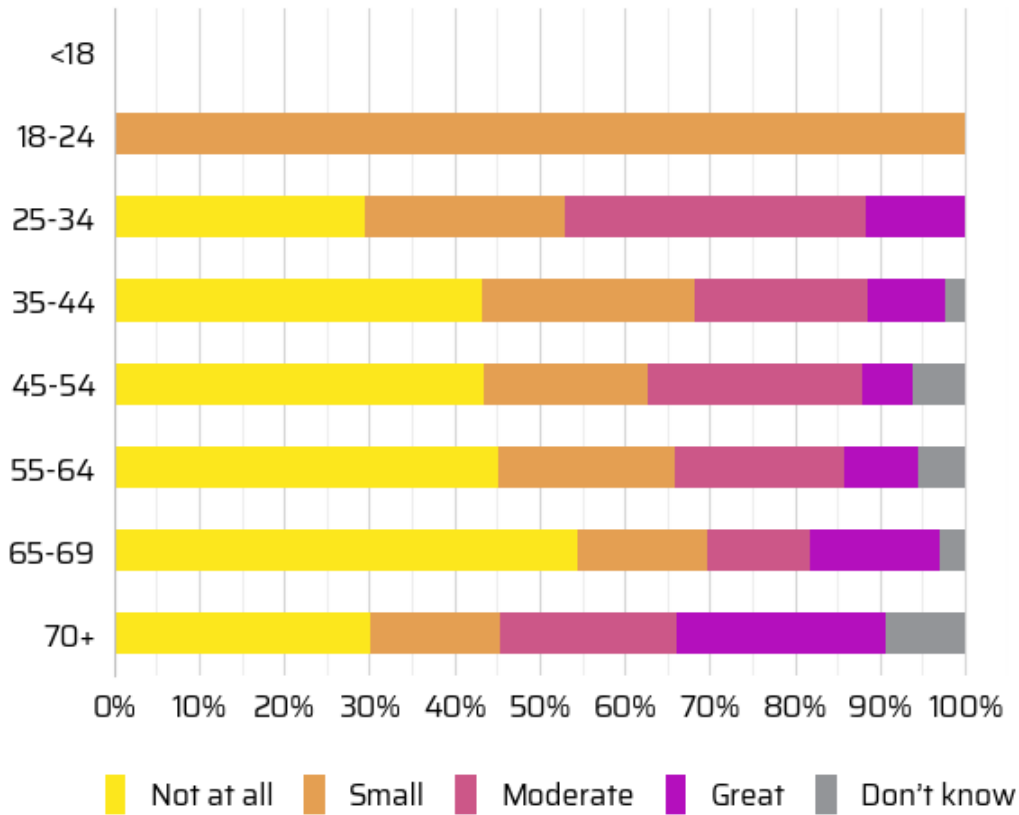


Figure 24 : Extent respondents reported their mental health needs were being met, broken down by age group.

Table 22 : 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	0	0.0
	Small	0	0.0
	Not at all	0	0.0

18-24	Don't know	0	0.0
	Great	0	0.0
	Moderate	0	0.0
	Small	1	100.0
	Not at all	0	0.0
25-34	Don't know	0	0.0
	Great	2	11.76
	Moderate	6	35.29
	Small	4	23.53
	Not at all	5	29.41
35-44	Don't know	1	2.27
	Great	4	9.09
	Moderate	9	20.45
	Small	11	25.0
	Not at all	19	43.18
45-54	Don't know	6	6.06
	Great	6	6.06
	Moderate	25	25.25
	Small	19	19.19
	Not at all	43	43.43
55-64	Don't know	7	5.56
	Great	11	8.73
	Moderate	25	19.84
	Small	26	20.63
	Not at all	57	45.24
65-69	Don't know	1	3.03
	Great	5	15.15
	Moderate	4	12.12
	Small	5	15.15

	Not at all	18	54.55
	Don't know	5	9.43
	Great	13	24.53
70+	Moderate	11	20.75
	Small	8	15.09
	Not at all	16	30.19

Extent mental health needs are met by gender.

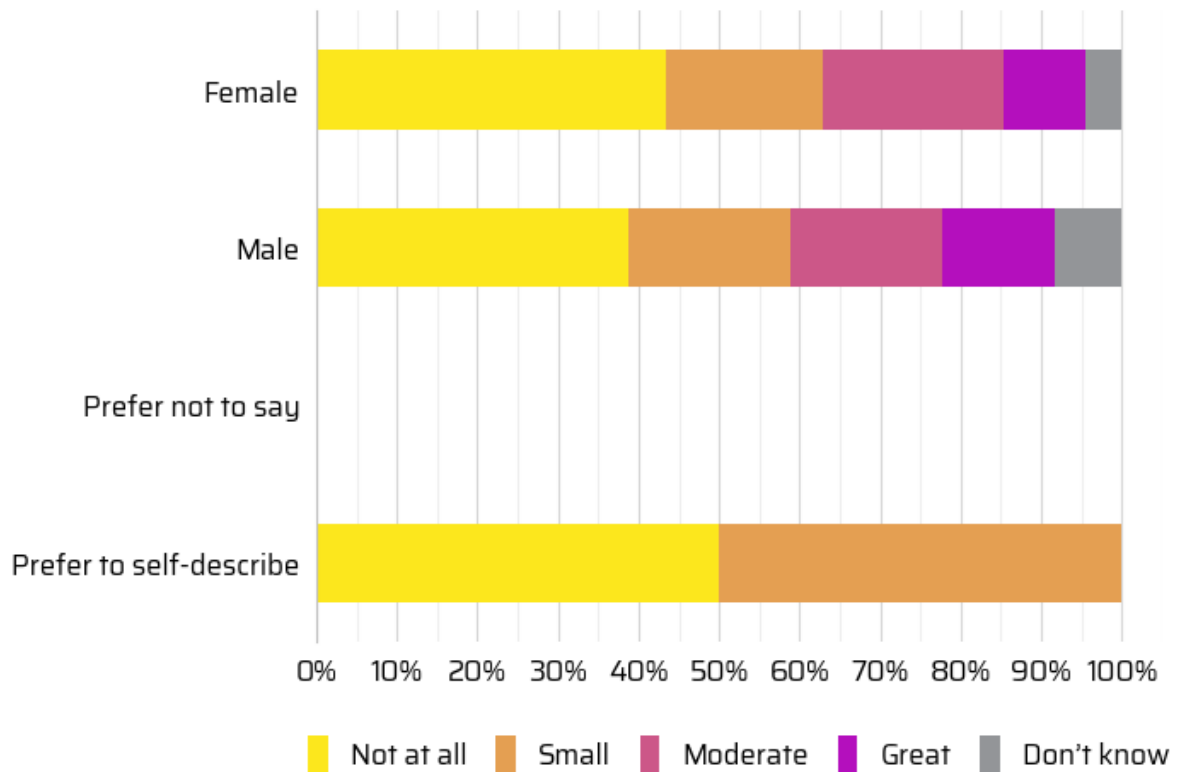


Figure 25 : Extent respondents reported their mental health needs were being met, broken down by gender.

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

Gender	Needs met	Respondents	Percentage
Female	Don't know	13	4.55

	Great	29	10.14
	Moderate	64	22.38
	Small	56	19.58
	Not at all	124	43.36
	Don't know	7	8.24
Male	Great	12	14.12
	Moderate	16	18.82
	Small	17	20.0
	Not at all	33	38.82
	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	0	0.0
	Moderate	0	0.0
	Small	1	50.0
	Not at all	1	50.0
	Don't know	0	0.0

Extent mental health needs are met by employment status

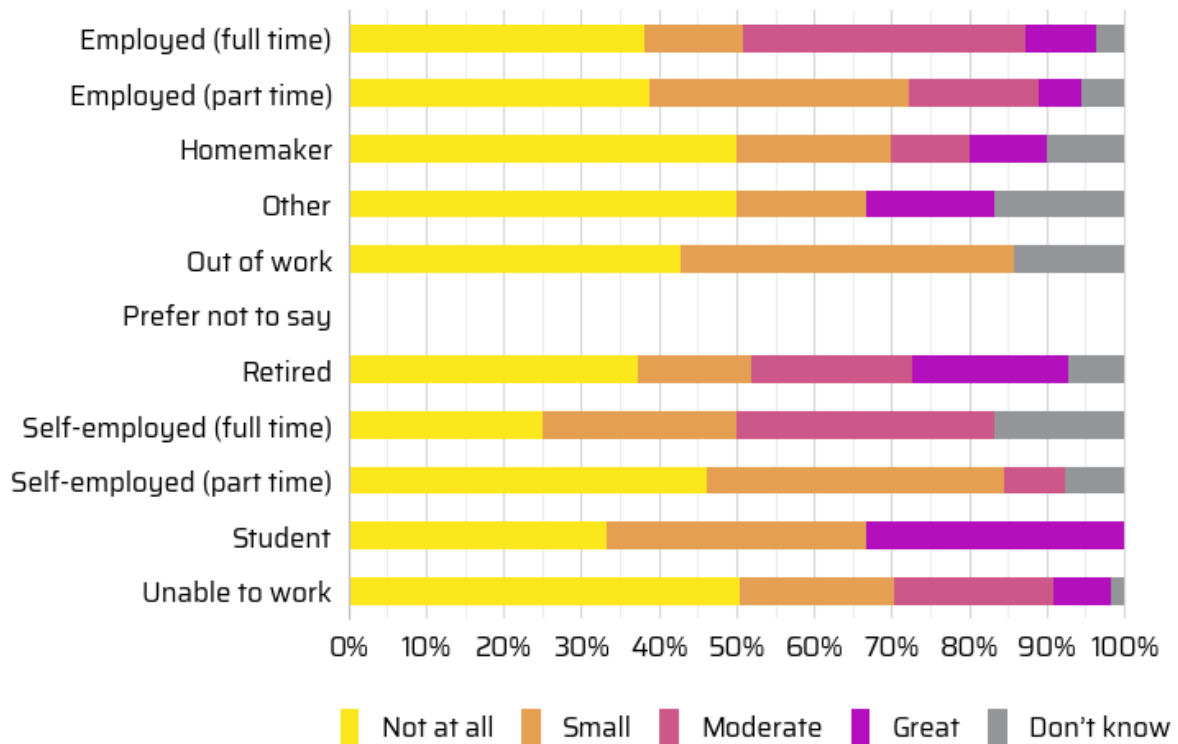


Figure 26 : Extent respondents reported their mental health needs were being met, broken down by employment status.

Table 24 : 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	2	3.64
	Great	5	9.09
	Moderate	20	36.36
	Small	7	12.73
	Not at all	21	38.18
Employed (part time)	Don't know	2	5.56
	Great	2	5.56
	Moderate	6	16.67
	Small	12	33.33
	Not at all	14	38.89

	Don't know	1	10.0
	Great	1	10.0
Homemaker	Moderate	1	10.0
	Small	2	20.0
	Not at all	5	50.0
	Don't know	1	16.67
	Great	1	16.67
Other	Moderate	0	0.0
	Small	1	16.67
	Not at all	3	50.0
	Don't know	1	14.29
	Great	0	0.0
Out of work	Moderate	0	0.0
	Small	3	42.86
	Not at all	3	42.86
	Don't know	0	0.0
	Great	0	0.0
Prefer not to say	Moderate	0	0.0
	Small	0	0.0
	Not at all	0	0.0
	Don't know	8	7.27
	Great	22	20.0
Retired	Moderate	23	20.91
	Small	16	14.55
	Not at all	41	37.27
	Don't know	2	16.67
Self-employed (full time)	Great	0	0.0
	Moderate	4	33.33
	Small	3	25.0

	Not at all	3	25.0
	Don't know	1	7.69
Self-employed (part time)	Great	0	0.0
	Moderate	1	7.69
	Small	5	38.46
	Not at all	6	46.15
	Don't know	0	0.0
Student	Great	1	33.33
	Moderate	0	0.0
	Small	1	33.33
	Not at all	1	33.33
	Don't know	2	1.65
Unable to work	Great	9	7.44
	Moderate	25	20.66
	Small	24	19.83
	Not at all	61	50.41
	Don't know		

Extent mental health needs are met by number of dependents.

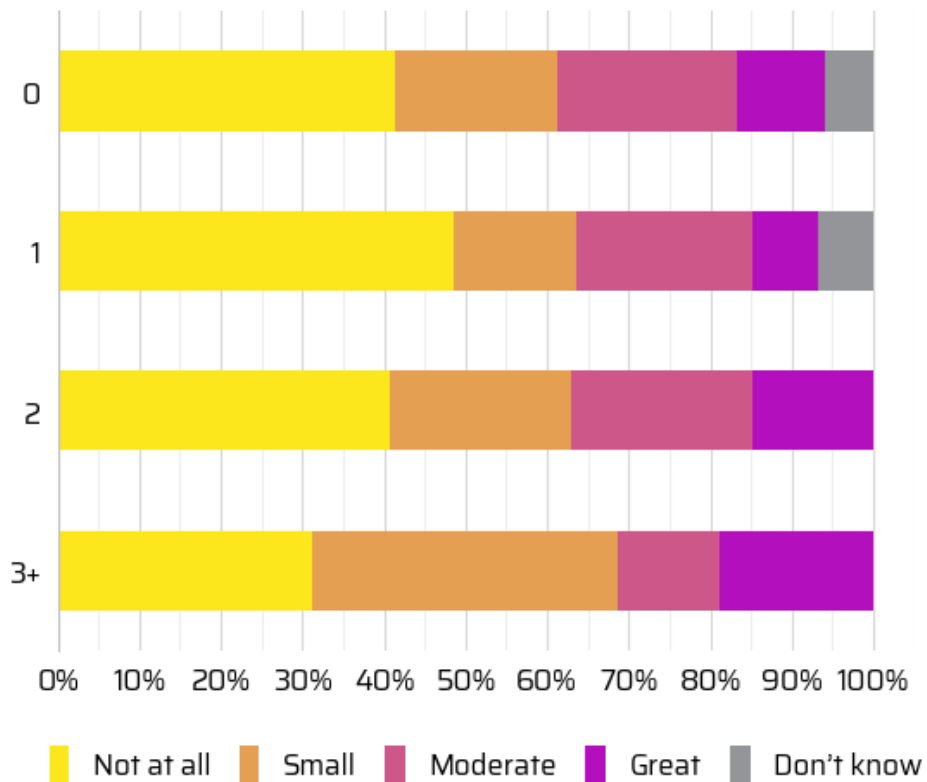


Figure 27 : Extent respondents reported their mental health needs were being met, broken down by number of dependents.

Table 25 : 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	15	5.86
	Great	28	10.94
	Moderate	56	21.88
	Small	51	19.92
	Not at all	106	41.41
1	Don't know	5	6.76
	Great	6	8.11
	Moderate	16	21.62
	Small	11	14.86

	Not at all	36	48.65
	Don't know	0	0.0
	Great	4	14.81
2	Moderate	6	22.22
	Small	6	22.22
	Not at all	11	40.74
	Don't know	0	0.0
	Great	3	18.75
3+	Moderate	2	12.5
	Small	6	37.5
	Not at all	5	31.25

Frequency NHS A&E / emergency services were sought

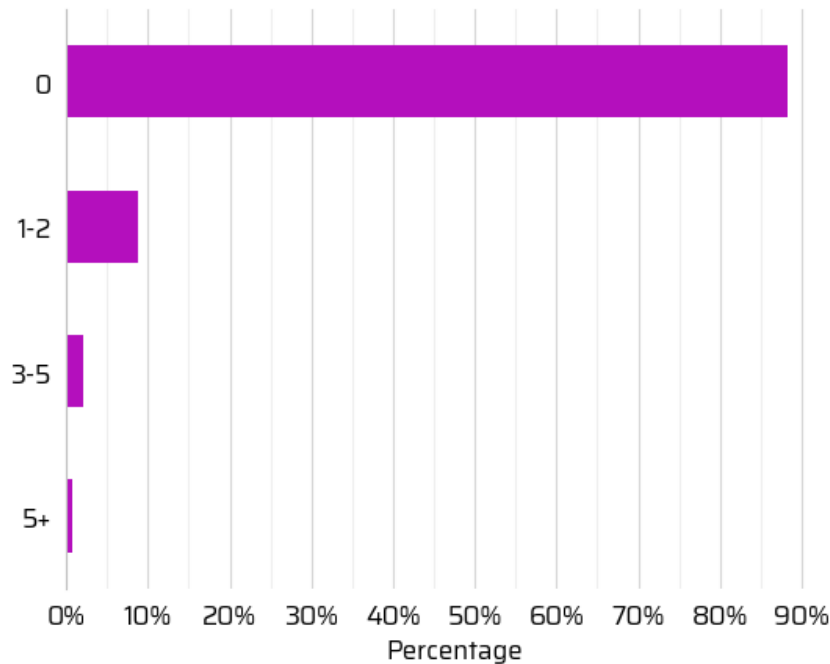


Figure 28 : Frequency that NHS A&E/emergency services were sought in the last eight weeks.

Table 26 : Frequency that NHS A&E/emergency services were sought in the last eight weeks.

Frequency	Respondents	Percentage
0	329	88.2

1-2	33	8.85
3-5	8	2.14
5+	3	0.8

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

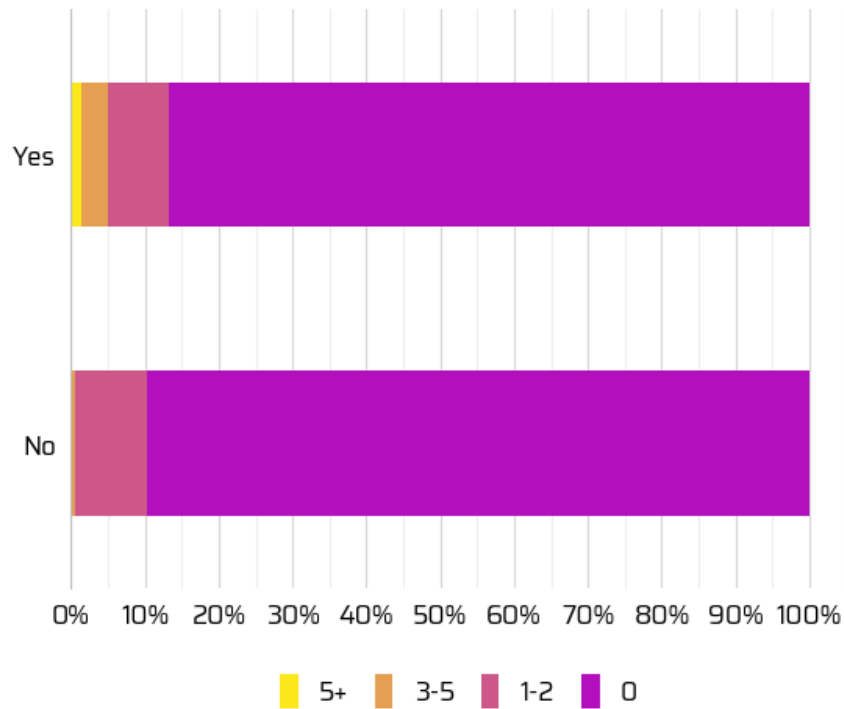


Figure 29 : Frequency that NHS A&E/emergency services were sought, broken down by whether diagnosed with multiple neurological conditions.

Table 27 : 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	178	86.83
	1-2	17	8.29
	3-5	7	3.41
	5+	3	1.46
No	0	150	89.82
	1-2	16	9.58

3-5	1	0.6
5+	0	0.0

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

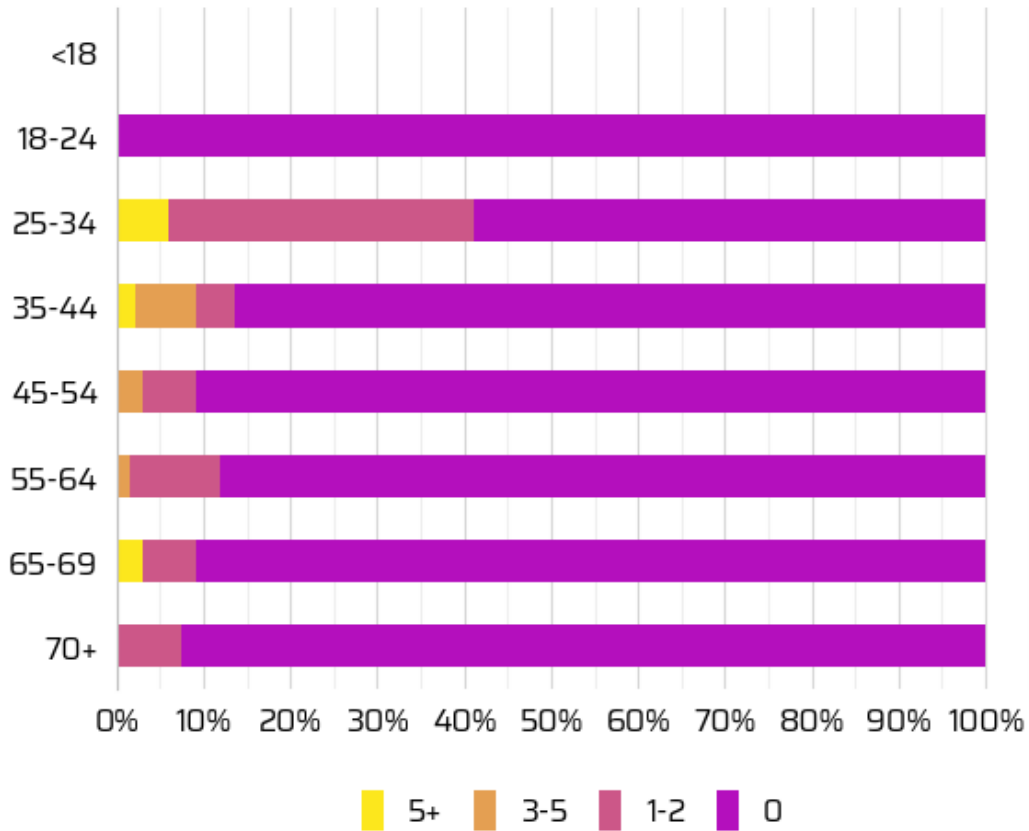


Figure 30 : Frequency that NHS A&E/emergency services were sought, broken down by age group.

Table 28 : Frequency that NHS A&E/emergency services were sought, broken down by age group.

Age	Frequency	Respondents	Percentage
<18	0	0	0.0
	1-2	0	0.0
	3-5	0	0.0
	5+	0	0.0
18-24	0	1	100.0
	1-2	0	0.0
	3-5	0	0.0
	5+	0	0.0

25-34	0	10	58.82
	1-2	6	35.29
	3-5	0	0.0
	5+	1	5.88
35-44	0	38	86.36
	1-2	2	4.55
	3-5	3	6.82
	5+	1	2.27
45-54	0	90	90.91
	1-2	6	6.06
	3-5	3	3.03
	5+	0	0.0
55-64	0	111	88.1
	1-2	13	10.32
	3-5	2	1.59
	5+	0	0.0
65-69	0	30	90.91
	1-2	2	6.06
	3-5	0	0.0
	5+	1	3.03
70+	0	49	92.45
	1-2	4	7.55
	3-5	0	0.0
	5+	0	0.0

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

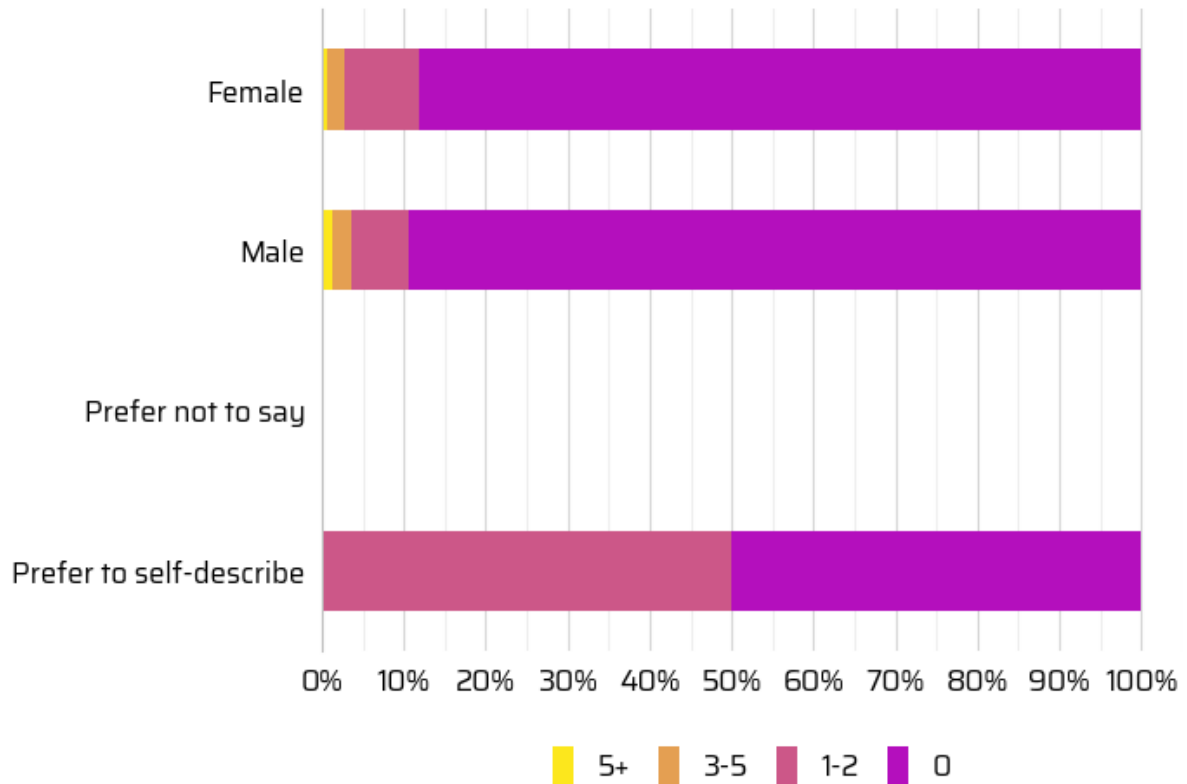


Figure 31 : Frequency that NHS A&E/emergency services were sought, broken down by gender.

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

Gender	Frequency	Respondents	Percentage
Female	0	252	88.11
	1-2	26	9.09
	3-5	6	2.1
	5+	2	0.7
Male	0	76	89.41
	1-2	6	7.06
	3-5	2	2.35
	5+	1	1.18
Prefer not to say	0	0	0.0
	1-2	0	0.0
	3-5	0	0.0

	5+	0	0.0
	0	1	50.0
Prefer to self-describe	1-2	1	50.0
	3-5	0	0.0
	5+	0	0.0

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

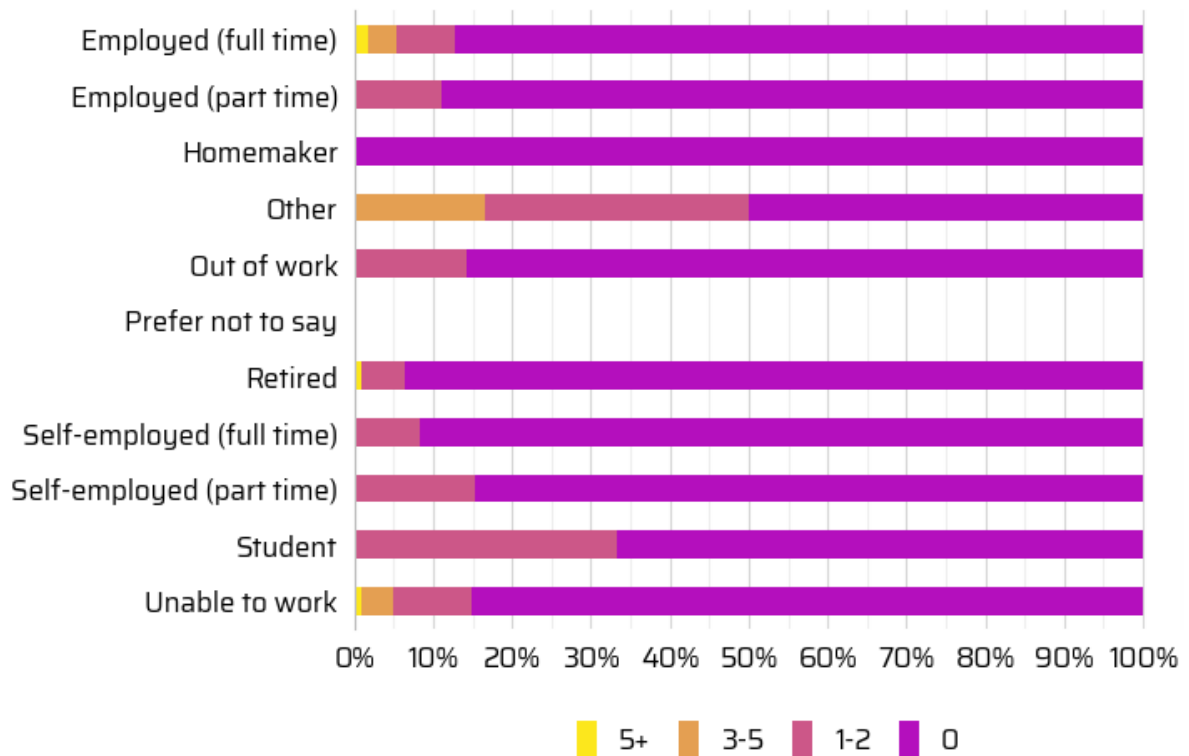


Figure 32 : Frequency that NHS A&E/emergency services were sought, broken down by employment status.

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

Employment status	Frequency	Respondents	Percentage
Employed (full time)	0	48	87.27
	1-2	4	7.27
	3-5	2	3.64
	5+	1	1.82

	0	32	88.89
Employed (part time)	1-2	4	11.11
	3-5	0	0.0
	5+	0	0.0
	0	10	100.0
Homemaker	1-2	0	0.0
	3-5	0	0.0
	5+	0	0.0
	0	3	50.0
Other	1-2	2	33.33
	3-5	1	16.67
	5+	0	0.0
	0	6	85.71
Out of work	1-2	1	14.29
	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	103	93.64
Retired	1-2	6	5.45
	3-5	0	0.0
	5+	1	0.91
	0	11	91.67
Self-employed (full time)	1-2	1	8.33
	3-5	0	0.0
	5+	0	0.0
	0	0	0.0

		0	11	84.62
Self-employed (part time)		1-2	2	15.38
		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	103	85.12
Unable to work		1-2	12	9.92
		3-5	5	4.13
		5+	1	0.83
		0		

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

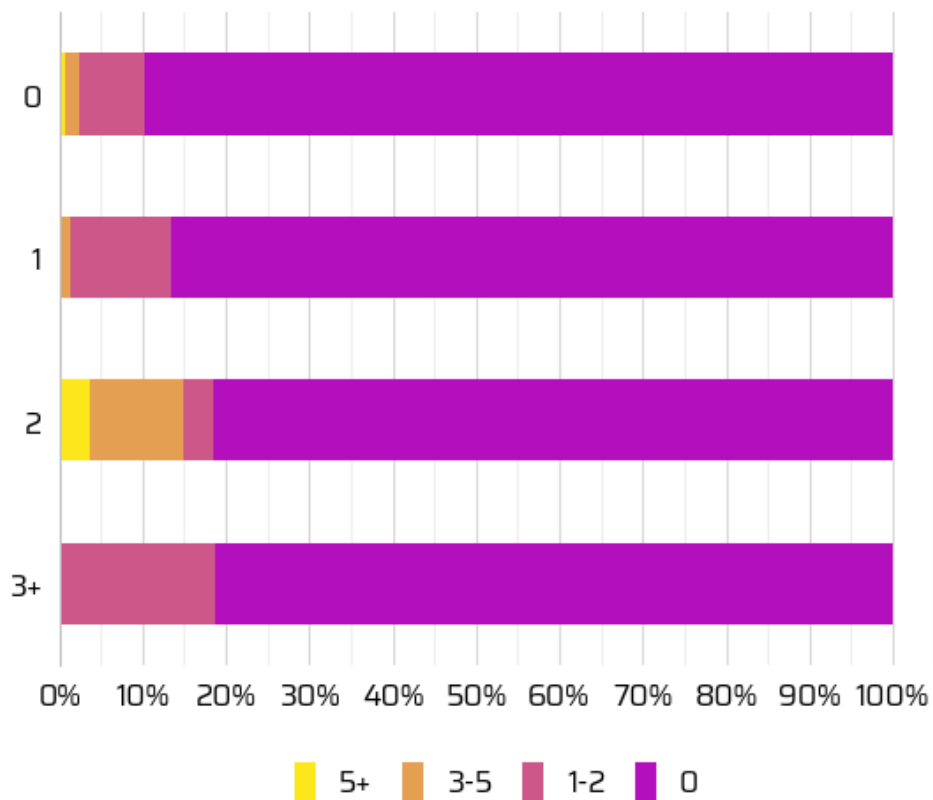


Figure 33 : Frequency that NHS A&E/emergency services were sought, broken down by number of dependents.

Table 31 : Frequency that NHS A&E/emergency services were sought, broken down by number of dependents.

Number of dependents	Frequency	Respondents	Percentage
0	0	230	89.84
	1-2	20	7.81
	3-5	4	1.56
	5+	2	0.78
1	0	64	86.49
	1-2	9	12.16
	3-5	1	1.35
	5+	0	0.0

2	0	22	81.48
	1-2	1	3.7
	3-5	3	11.11
	5+	1	3.7
3+	0	13	81.25
	1-2	3	18.75
	3-5	0	0.0
	5+	0	0.0

Overall experience of health & care

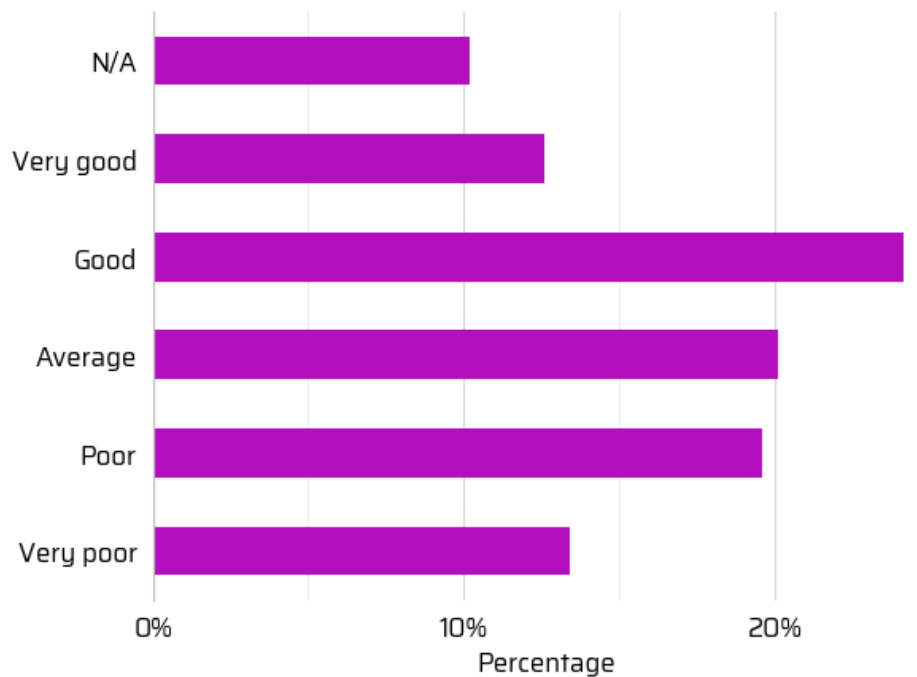


Figure 34 : Overall experience of health & care.

Table 32 : Overall experience of health & care.

Experience	Respondents	Percentage
N/A	38	10.19
Very good	47	12.6
Good	90	24.13
Average	75	20.11

Poor	73	19.57
Very poor	50	13.4

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

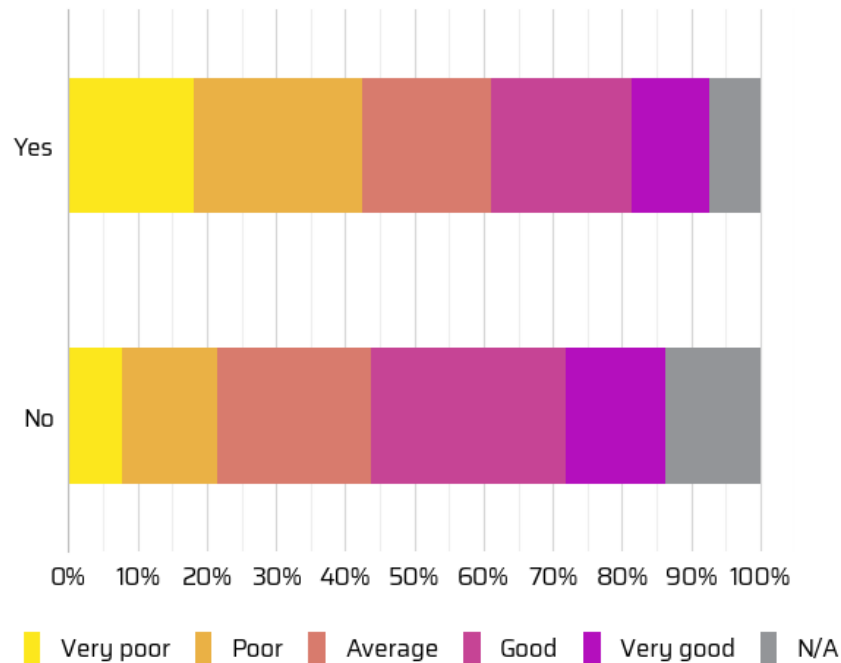


Figure 35 : Overall experience of health & care, broken down by whether diagnosed with multiple neurological conditions.

Table 33 : Overall experience of health & care, broken down by whether diagnosed with multiple neurological conditions.

Multiple neurological conditions	Experience	Respondents	Percentage
Yes	N/A	15	7.32
	Very good	23	11.22
	Good	42	20.49
	Average	38	18.54
	Poor	50	24.39
	Very poor	37	18.05
No	N/A	23	13.77

Very good	24	14.37
Good	47	28.14
Average	37	22.16
Poor	23	13.77
Very poor	13	7.78

Overall experience of health & care by age group

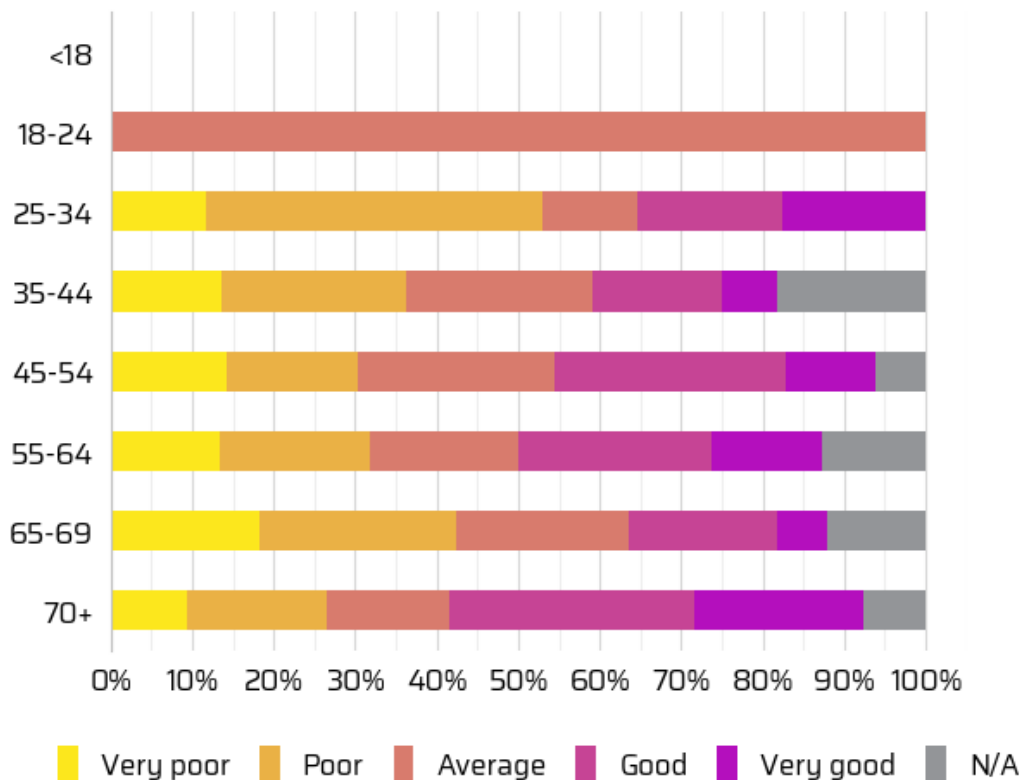


Figure 36 : Overall experience of health & care, broken down by age group.

Table 34 : Overall experience of health & care, broken down by age group.

Age	Experience	Respondents	Percentage
<18	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	0	0.0
	Very good	0	0.0
	Good	0	0.0
18-24	Average	1	100.0
	Poor	0	0.0
	Very poor	0	0.0
	N/A	0	0.0
	Very good	3	17.65
	Good	3	17.65
25-34	Average	2	11.76
	Poor	7	41.18
	Very poor	2	11.76
	N/A	8	18.18
	Very good	3	6.82
	Good	7	15.91
35-44	Average	10	22.73
	Poor	10	22.73
	Very poor	6	13.64
	N/A	6	6.06
	Very good	11	11.11
	Good	28	28.28
45-54	Average	24	24.24
	Poor	16	16.16
	Very poor	14	14.14
	N/A	16	12.7
55-64	Very good	17	13.49
	Good	30	23.81

	Average	23	18.25
	Poor	23	18.25
	Very poor	17	13.49
	N/A	4	12.12
	Very good	2	6.06
	Good	6	18.18
65-69	Average	7	21.21
	Poor	8	24.24
	Very poor	6	18.18
	N/A	4	7.55
	Very good	11	20.75
	Good	16	30.19
70+	Average	8	15.09
	Poor	9	16.98
	Very poor	5	9.43

Overall experience of health & care by gender

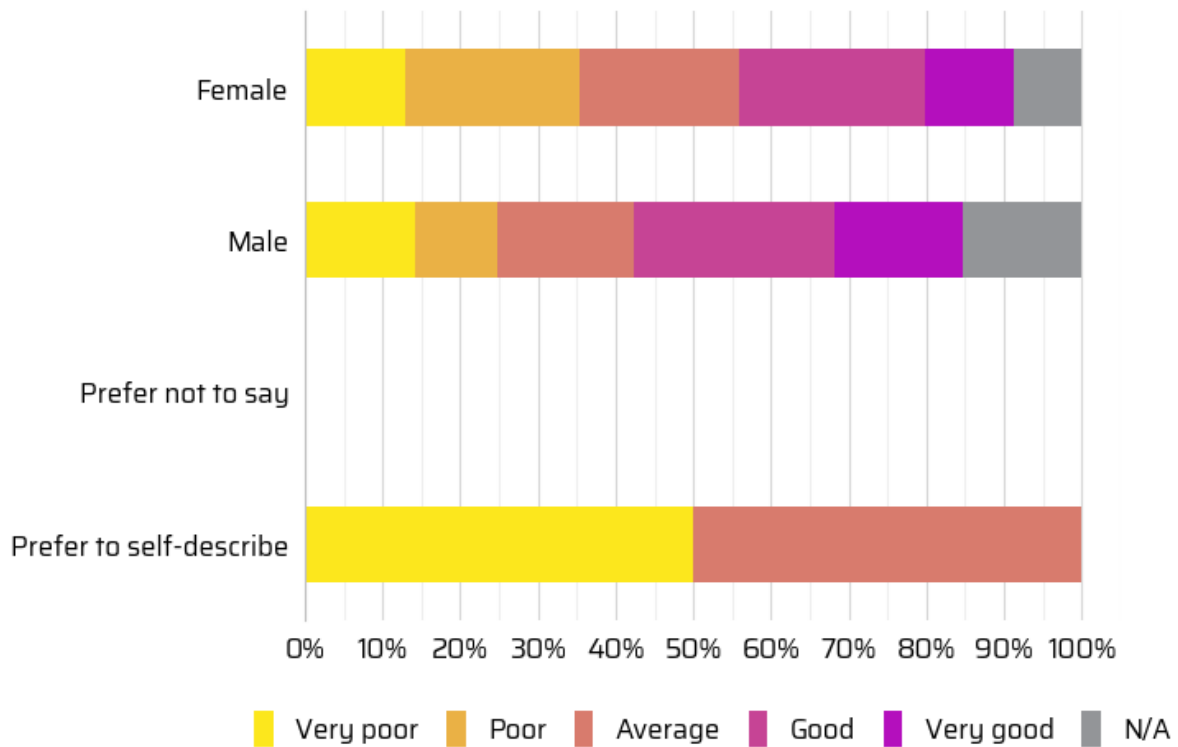


Figure 37 : Overall experience of health & care, broken down by gender.

Table 35 : Overall experience of health & care, broken down by gender.

Gender	Experience	Respondents	Percentage
Female	N/A	25	8.74
	Very good	33	11.54
	Good	68	23.78
	Average	59	20.63
	Poor	64	22.38
	Very poor	37	12.94
Male	N/A	13	15.29
	Very good	14	16.47
	Good	22	25.88
	Average	15	17.65
	Poor	9	10.59

	Very poor	12	14.12
	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	0	0.0
Prefer to self-describe	Very good	0	0.0
	Good	0	0.0
	Average	1	50.0
	Poor	0	0.0
	Very poor	1	50.0

Overall experience of health & care by employment status

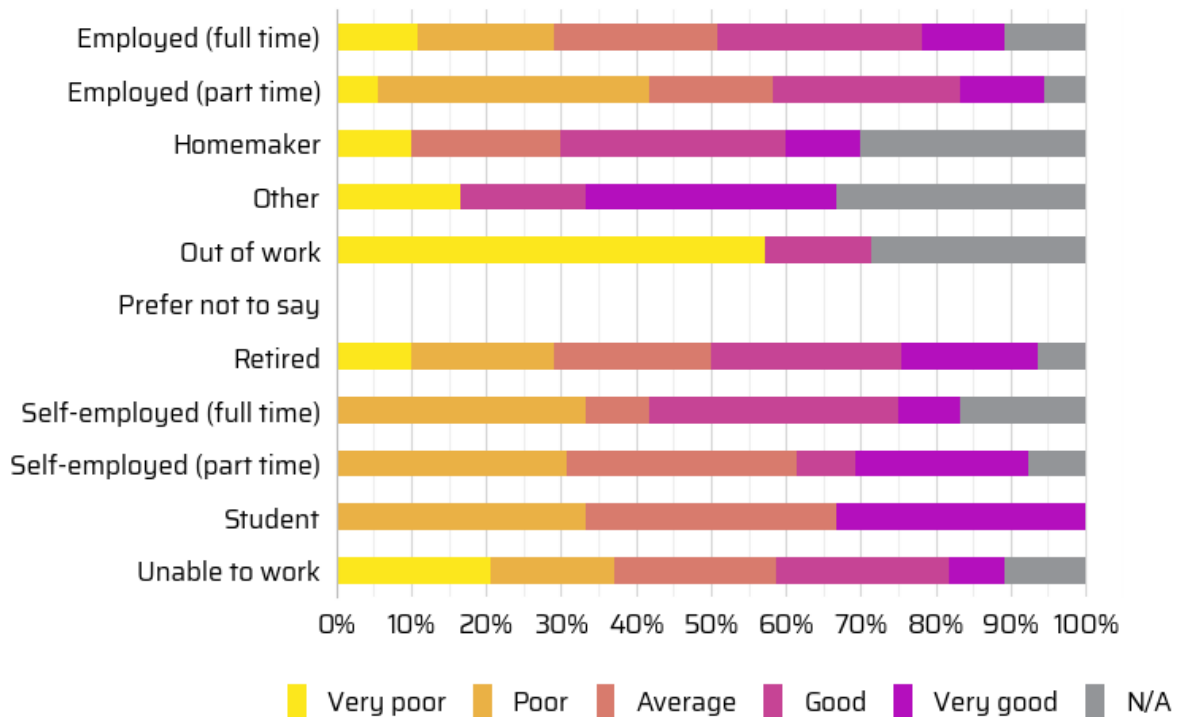


Figure 38 : Overall experience of health & care, broken down by employment status.

Table 36 : Overall experience of health & care, broken down by employment status.

Employment status	Experience	Respondents	Percentage
Employed (full time)	N/A	6	10.91
	Very good	6	10.91
	Good	15	27.27
	Average	12	21.82
	Poor	10	18.18
	Very poor	6	10.91
Employed (part time)	N/A	2	5.56
	Very good	4	11.11
	Good	9	25.0
	Average	6	16.67
	Poor	13	36.11
	Very poor	2	5.56
Homemaker	N/A	3	30.0
	Very good	1	10.0
	Good	3	30.0
	Average	2	20.0
	Poor	0	0.0
	Very poor	1	10.0
Other	N/A	2	33.33
	Very good	2	33.33
	Good	1	16.67
	Average	0	0.0
	Poor	0	0.0
	Very poor	1	16.67
Out of work	N/A	2	28.57
	Very good	0	0.0

	Good	1	14.29
	Average	0	0.0
	Poor	0	0.0
	Very poor	4	57.14
	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	6.36
	Very good	20	18.18
Retired	Good	28	25.45
	Average	23	20.91
	Poor	21	19.09
	Very poor	11	10.0
	N/A	2	16.67
	Very good	1	8.33
Self-employed (full time)	Good	4	33.33
	Average	1	8.33
	Poor	4	33.33
	Very poor	0	0.0
	N/A	1	7.69
	Very good	3	23.08
Self-employed (part time)	Good	1	7.69
	Average	4	30.77
	Poor	4	30.77
	Very poor	0	0.0

Student	N/A	0	0.0
	Very good	1	33.33
	Good	0	0.0
	Average	1	33.33
	Poor	1	33.33
	Very poor	0	0.0
Unable to work	N/A	13	10.74
	Very good	9	7.44
	Good	28	23.14
	Average	26	21.49
	Poor	20	16.53
	Very poor	25	20.66

Overall experience of health & care by number of dependents

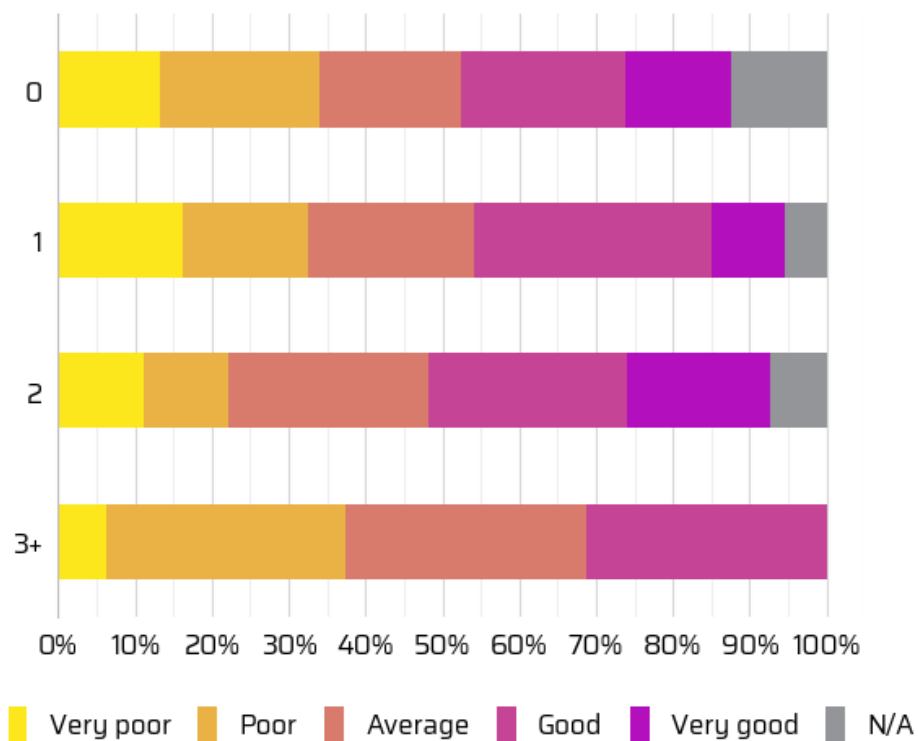


Figure 39 : Overall experience of health & care, broken down by number of dependents.

Table 37 : Overall experience of health & care, broken down by number of dependents.

Number of dependents	Experience	Respondents	Percentage
0	N/A	32	12.5
	Very good	35	13.67
	Good	55	21.48
	Average	47	18.36
	Poor	53	20.7
	Very poor	34	13.28
	1	N/A	4
Very good		7	9.46
Good		23	31.08
Average		16	21.62
Poor		12	16.22
Very poor		12	16.22
2	N/A	2	7.41
	Very good	5	18.52
	Good	7	25.93
	Average	7	25.93
	Poor	3	11.11
	Very poor	3	11.11
3+	N/A	0	0.0
	Very good	0	0.0
	Good	5	31.25
	Average	5	31.25
	Poor	5	31.25
	Very poor	1	6.25

Demographics

Sample size

Total number of respondents: 373

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 205 respondents, equating to 55.11% of the respondents that had answered this question, indicated that they have multiple (i.e., more than one) neurological conditions.

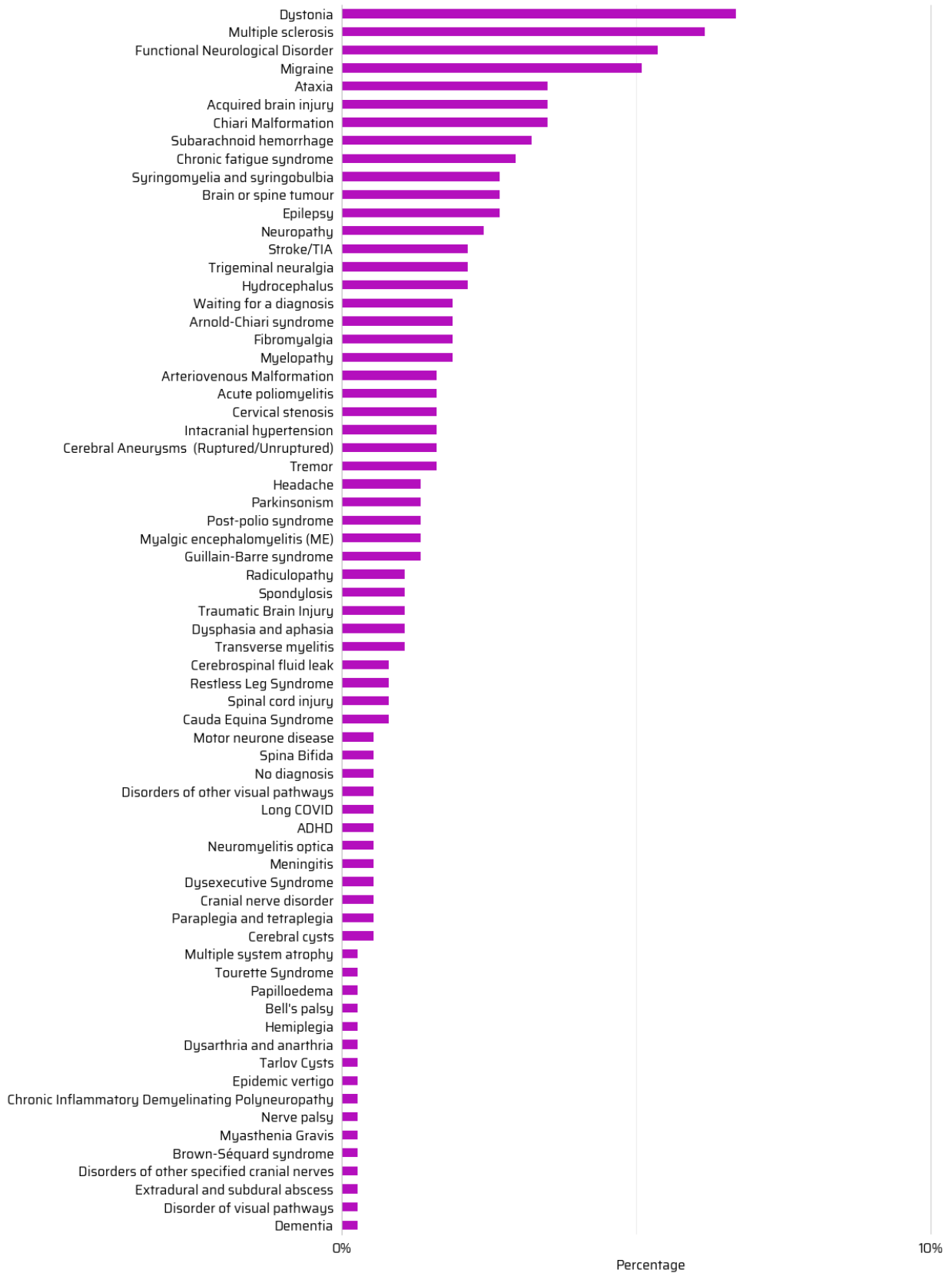


Figure 40 : Neurological conditions respondents had been diagnosed with.

Table 38 : Neurological conditions respondents had been diagnosed with.

Condition	Respondents	Percentage
Dystonia	25	6.7
Multiple sclerosis	23	6.17
Functional Neurological Disorder	20	5.36
Migraine	19	5.09
Ataxia	13	3.49
Acquired brain injury	13	3.49
Chiari Malformation	13	3.49
Subarachnoid hemorrhage	12	3.22
Chronic fatigue syndrome	11	2.95
Syringomyelia and syringobulbia	10	2.68
Brain or spine tumour	10	2.68
Epilepsy	10	2.68
Neuropathy	9	2.41
Hydrocephalus	8	2.14
Stroke/TIA	8	2.14
Trigeminal neuralgia	8	2.14
Waiting for a diagnosis	7	1.88
Arnold-Chiari syndrome	7	1.88
Fibromyalgia	7	1.88
Myelopathy	7	1.88
Tremor	6	1.61
Cerebral Aneurysms (Ruptured/Unruptured)	6	1.61
Arteriovenous Malformation	6	1.61
Intacranial hypertension	6	1.61
Cervical stenosis	6	1.61
Acute poliomyelitis	6	1.61

Headache	5	1.34
Parkinsonism	5	1.34
Post-polio syndrome	5	1.34
Myalgic encephalomyelitis (ME)	5	1.34
Guillain-Barre syndrome	5	1.34
Spondylosis	4	1.07
Radiculopathy	4	1.07
Traumatic Brain Injury	4	1.07
Transverse myelitis	4	1.07
Dysphasia and aphasia	4	1.07
Cerebrospinal fluid leak	3	0.8
Restless Leg Syndrome	3	0.8
Spinal cord injury	3	0.8
Cauda Equina Syndrome	3	0.8
Cerebral cysts	2	0.54
Paraplegia and tetraplegia	2	0.54
Cranial nerve disorder	2	0.54
Dysexecutive Syndrome	2	0.54
Meningitis	2	0.54
Neuromyelitis optica	2	0.54
Spina Bifida	2	0.54
ADHD	2	0.54
Long COVID	2	0.54
Disorders of other visual pathways	2	0.54
Motor neurone disease	2	0.54
No diagnosis	2	0.54
Disorder of visual pathways	1	0.27
Extradural and subdural abscess	1	0.27

Disorders of other specified cranial nerves	1	0.27
Brown-Séquard syndrome	1	0.27
Myasthenia Gravis	1	0.27
Nerve palsy	1	0.27
Chronic Inflammatory Demyelinating Polyneuropathy	1	0.27
Multiple system atrophy	1	0.27
Tarlov Cysts	1	0.27
Dysarthria and anarthria	1	0.27
Hemiplegia	1	0.27
Bell's palsy	1	0.27
Papilloedema	1	0.27
Tourette Syndrome	1	0.27
Epidemic vertigo	1	0.27
Dementia	1	0.27

Multiple neurological conditions

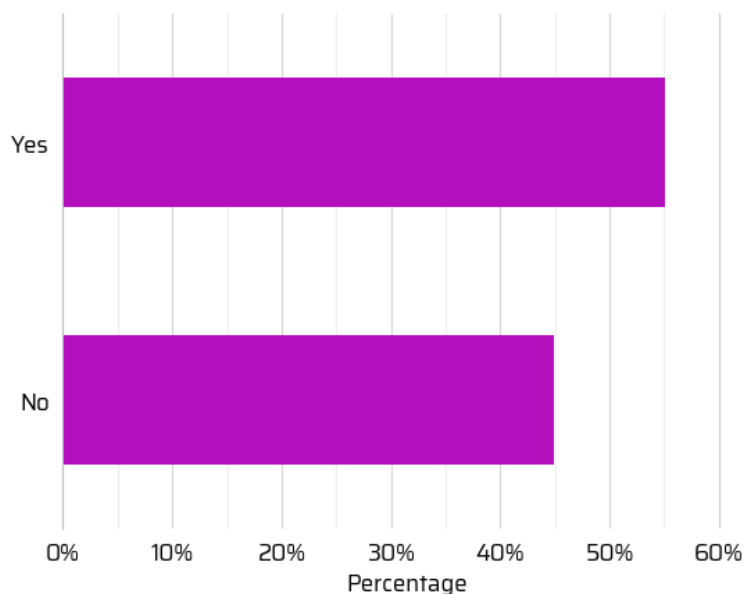


Figure 41 : Whether respondents were diagnosed with multiple neurological conditions.

Table 39 : Whether respondents were diagnosed with multiple neurological conditions.

Multiple neurological conditions	Respondents	Percentage
Yes	205	55.11
No	167	44.89

Number of non-neurological co-occurring conditions

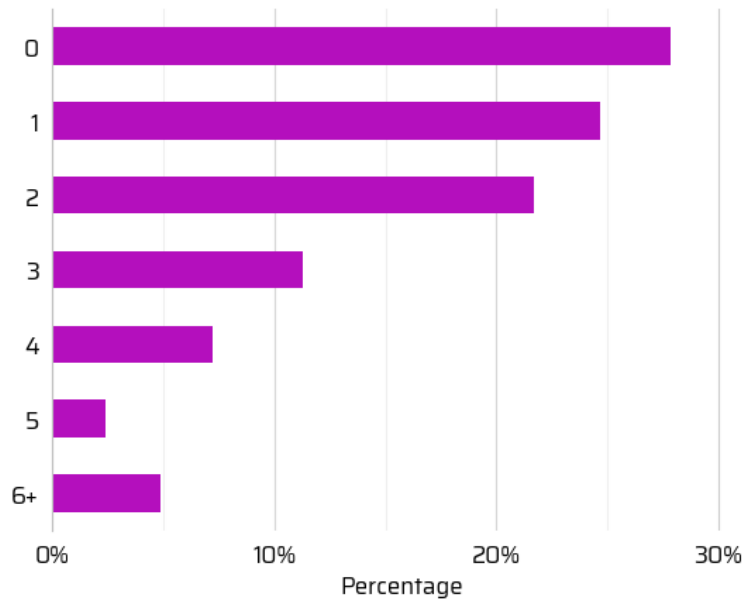


Figure 42 : Number of non-neurological conditions that respondents were diagnosed with that co-occur with their neurological condition(s).

Table 40 : Number of non-neurological conditions that respondents were diagnosed with that co-occur with their neurological condition(s).

Number of conditions	Respondents	Percentage
0	104	27.88
1	92	24.66
2	81	21.72
3	42	11.26
4	27	7.24
5	9	2.41
6+	18	4.83

Age

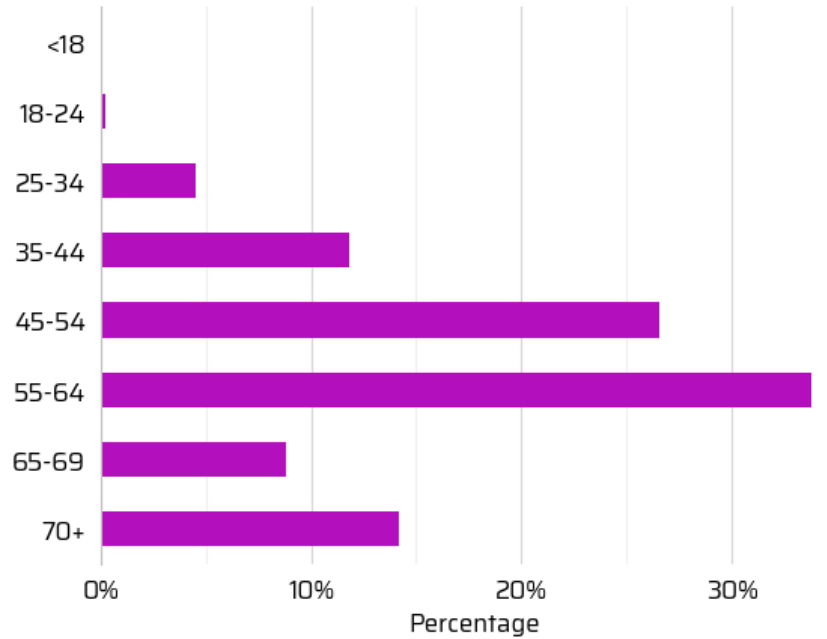


Figure 43 : Age of respondents.

Table 41: Age of respondents.

Age	Respondents	Percentage
<18	0	0.0
18-24	1	0.27
25-34	17	4.56
35-44	44	11.8
45-54	99	26.54
55-64	126	33.78
65-69	33	8.85
70+	53	14.21

Gender

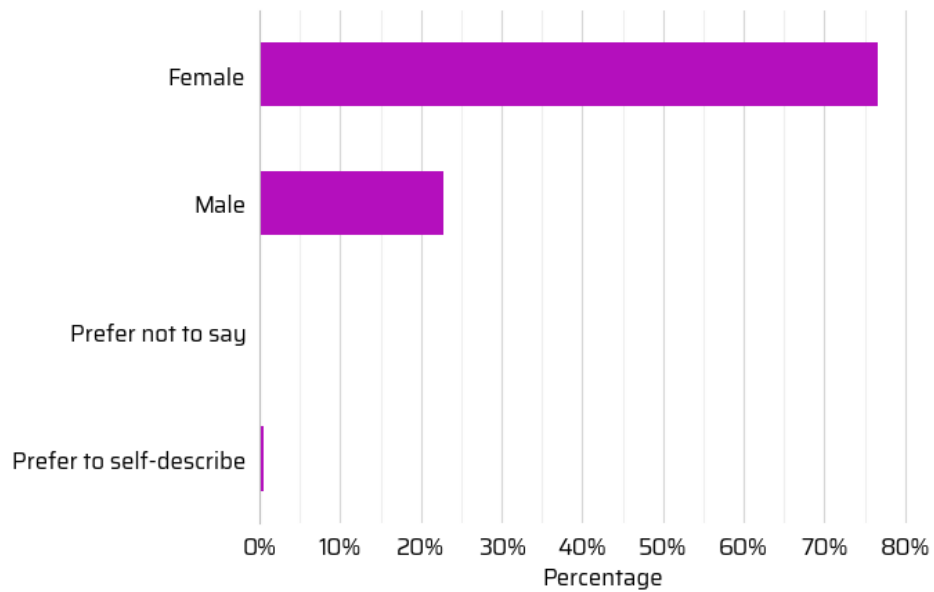


Figure 44 : Gender of respondents.

Table 42 : Gender of respondents.

Gender	Respondents	Percentage
Female	286	76.68
Male	85	22.79
Prefer not to say	0	0.0
Prefer to self-describe	2	0.54

Sexual orientation

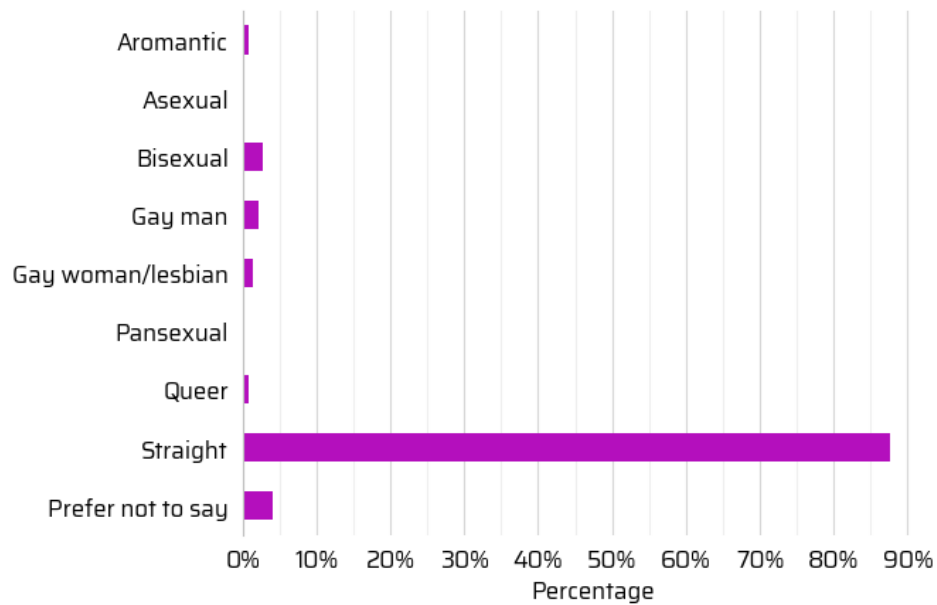


Figure 45 : Sexual orientation of respondents.

Table 43 : Sexual orientation of respondents.

Sexual orientation	Respondents	Percentage
Aromantic	3	0.81
Asexual	1	0.27
Bisexual	10	2.7
Gay man	8	2.16
Gay woman/lesbian	5	1.35
Pansexual	1	0.27
Queer	3	0.81
Straight	325	87.6
Prefer not to say	15	4.04

Age at diagnosis

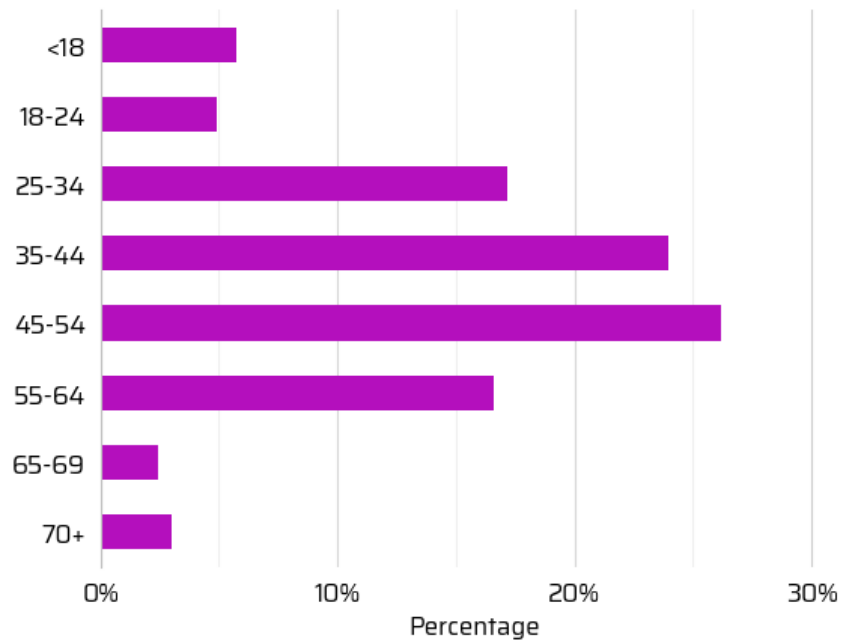


Figure 46 : Age of respondents when they were first diagnosed with a neurological condition.

Table 44 : Age of respondents when they were first diagnosed with a neurological condition.

Age	Respondents	Percentage
<18	21	5.72
18-24	18	4.9
25-34	63	17.17
35-44	88	23.98
45-54	96	26.16
55-64	61	16.62
65-69	9	2.45
70+	11	3.0

Location



Figure 47: Location of the respondents distributed across the UK.

Table 45: Location of the respondents distributed across the UK.

Regions	Respondents	Percentage
Southeast	64	17.98
Midlands	59	16.57
Northeast and Yorkshire	46	12.92
East of England	42	11.8
Southwest	41	11.52
London	32	8.99
Northwest	26	7.3
Scotland	26	7.3
Wales	11	3.09
Northern Ireland	6	1.69
Channel Islands	2	0.56
Isle of Man	1	0.28

NB: England is further divided into "NHS England Regions". 17 postcodes provided by the respondents were invalid, thus they are not included in this map and table.

Employment status

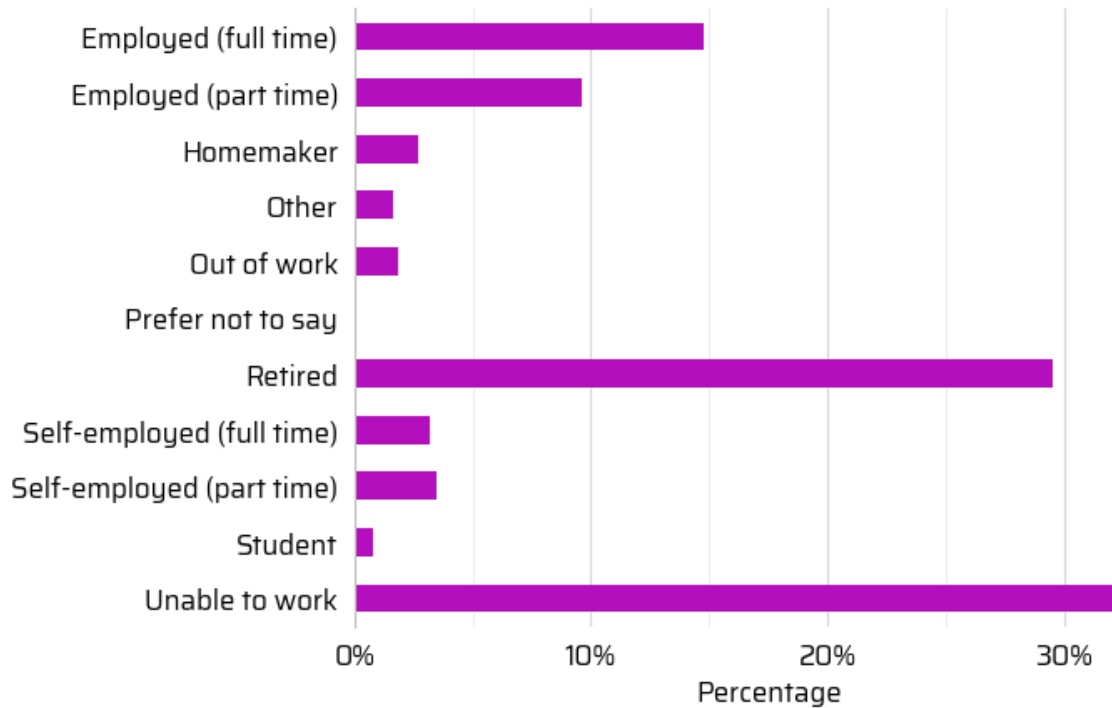


Figure 48 : Employment status of respondents.

Table 46 : Employment status of respondents.

Employment status	Respondents	Percentage
Employed (full time)	55	14.75
Employed (part time)	36	9.65
Homemaker	10	2.68
Other	6	1.61
Out of work	7	1.88
Prefer not to say	0	0.0
Retired	110	29.49
Self-employed (full time)	12	3.22
Self-employed (part time)	13	3.49
Student	3	0.8
Unable to work	121	32.44

Ethnic group

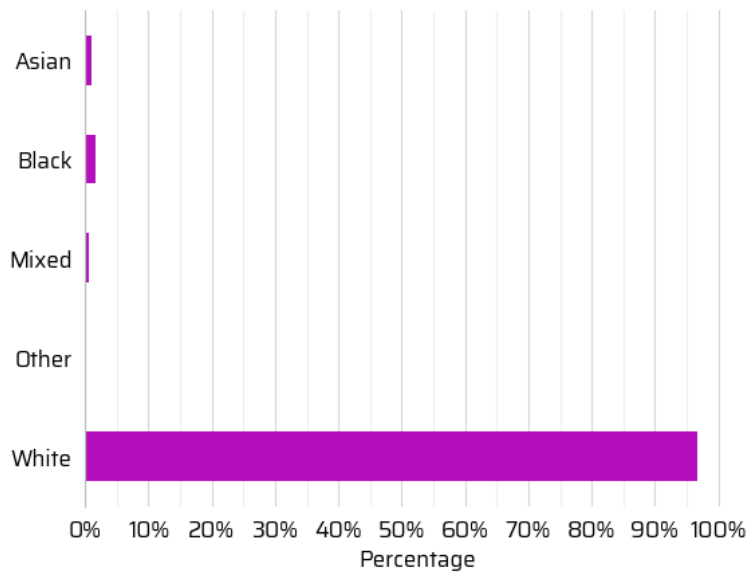


Figure 49 : Ethnic group of respondents.

Table 47 : Ethnic group of respondents.

Ethnic group	Respondents	Percentage
Asian	4	1.07
Black	6	1.61
Mixed	2	0.54
Other	0	0.0
White	361	96.78

Number of dependents

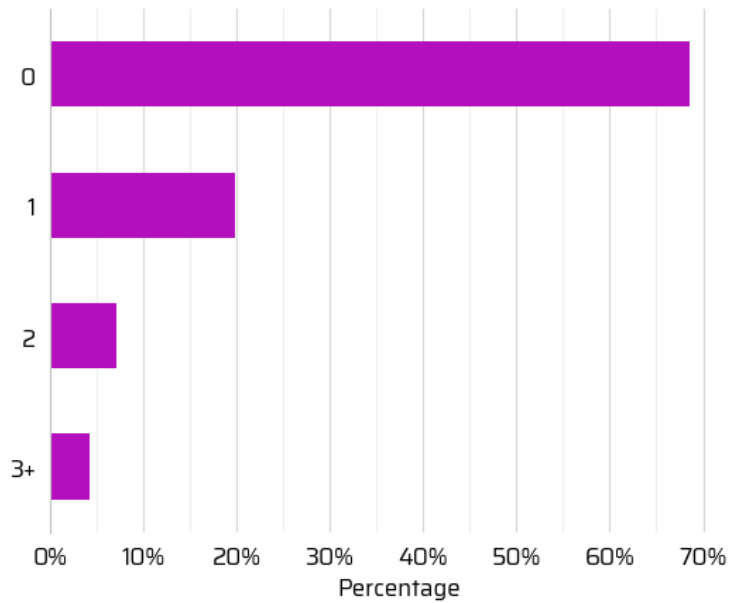


Figure 50 : Number of dependents of respondents.

Table 48 : Number of dependents of respondents.

Number of dependents	Respondents	Percentage
0	256	68.63
1	74	19.84
2	27	7.24
3+	16	4.29

Receiving care or support

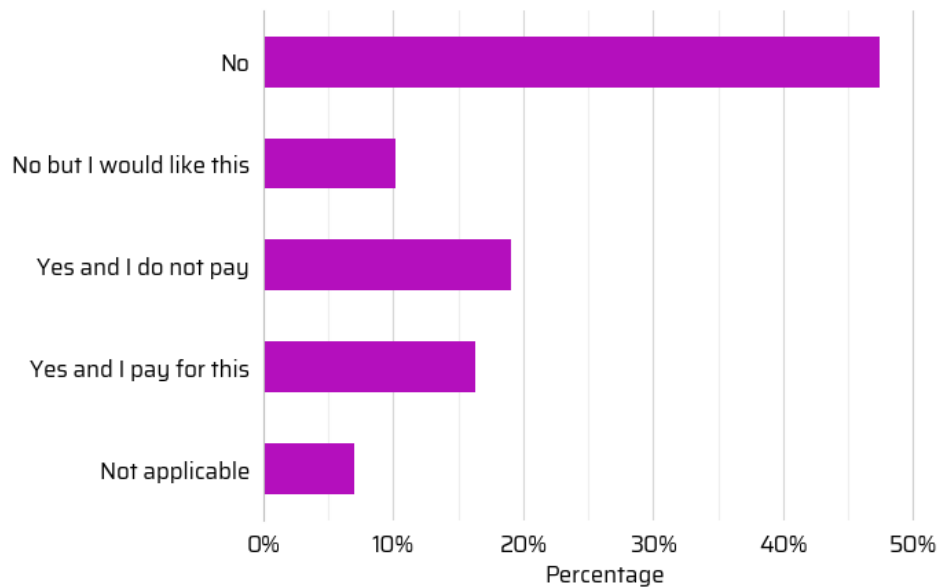


Figure 51: Whether respondents receiving care or support.

Table 49: Whether respondents receiving care or support.

Receive care/support	Respondents	Percentage
No	177	47.45
No but I would like this	38	10.19
Yes and I do not pay	71	19.03
Yes and I pay for this	61	16.35
Not applicable	26	6.97

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	3
	4	5	6+	

Thinking about your employment status, do you agree or disagree with the following statements?		
I have been able to continue working despite having a neurological condition.	Agree	Neither agree nor disagree
	Disagree	Not applicable
I have stopped working because of the symptoms of my neurological condition.	Agree	Neither agree nor disagree
	Disagree	Not applicable
I have had to leave a job because of my employer's failure to make reasonable adjustments.	Agree	Neither agree nor disagree
	Disagree	Not applicable
I have been discriminated against at work due to attitudes towards my neurological condition.	Agree	Neither agree nor disagree
	Disagree	Not applicable
My manager/colleagues don't understand the challenge of my neurological condition.	Agree	Neither agree nor disagree
	Disagree	Not applicable
I received the support I needed to retire from work "well".	Agree	Neither agree nor disagree
	Disagree	Not applicable
How would you describe the impacts of your neurological condition on your employment?	Free text	
In your opinion, how could an employer and workplace show they are inclusive of people affected by neurological conditions?	Free text	
About your recent experiences of treatment and support		

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

	Didn't see or speak to anyone			
How many times have you sought A&E/emergency support from the NHS as a result of your neurological condition in the last eight weeks?	None	1-2 times	3-5 times	5 or more times
Have you had any medical appointments (including remote appointments) in the last eight weeks?	Yes	No	Don't Know	
How many medical appointments have you had in the last eight weeks?	0	1	2	3
	4	5	6+	
Who was your first medical appointment with?	Neurologist			
	Specialist Nurse			
	Physiotherapist			
	Speech and Language Therapist			
	Occupational Therapist			
	Psychologist/ Psychiatrist			
	GP			
	Social Services			
	Neurosurgery			
	Other Allied Health Professional (AHP)			
How was your first medical appointment delivered?	Other			
	Phone			
	Videoconference			
	Via text/WhatsApp			
	Face to face			
How helpful was your first medical appointment?	Other			
	It was helpful			
	It was not helpful			
Who was your second medical appointment with?	Don't Know			
	Neurologist			
	Specialist Nurse			

	Physiotherapist
	Speech and Language Therapist
	Occupational Therapist
	Psychologist/ Psychiatrist
	GP
	Social Services
	Neurosurgery
	Other Allied Health Professional (AHP)
	Other
How was your 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			
	Student			
	Out of work			
	Unable to work			
	Retired			
	Prefer not to say			
	Other			
How many dependents live with you?	1	2	3	4
	5	6+		
Do you receive any care or support at home for your day-to-day life?	Yes and I pay for this			
	Yes and I do not pay			
	No but I would like this			
	No			
	Not applicable			
Communicating with you.				
What is your first name?	Free text			

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

Appendix B - List of 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
Intracranial hypertension	Intracranial abscess and granuloma	Intracranial and intraspinal abscess and granuloma in diseases classified elsewhere	Intracranial and intraspinal phlebitis and thrombophlebitis	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	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				

