



**March – April 2024 Full Insights Report**  
**The impact of long waits for NHS care on people affected by neurological conditions**



## **About NeuroLifeNow**

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

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

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

## Foreword

Over the summer, Lord Darzi, a former health minister and surgeon, was commissioned to undertake an independent analysis of the NHS in England. The review, entitled “Independent Investigation of the NHS in England” was published in September. It argues the NHS is facing rising demand for care as people live longer in ill health, coupled with low productivity in hospitals and poor staff morale. Importantly, he said: “Nothing that I have found draws into question the principles of a health service that is taxpayer-funded, free at the point of use, and based on need not ability to pay.”

The report essentially confirms much of what we already know and what is spelled out in this report – that many people, including people affected by neurological conditions, experience long waits for specialist input, poorly coordinated care and that the voice of ‘patients’ needs to be louder in policymaking.

The Lord Darzi review comes ahead of a new 10-year plan for the NHS in England, which will now be delivered before Spring 2025. This new report, which includes experience of waiting for care from more than 1000 people, provides timely input into that plan, and lessons for policymakers across the UK.

### Too many people are experiencing long waits

More than half of those who shared their experiences via NeuroLifeNow were waiting for NHS care. In England, at the same time the questionnaire was live, more than 230,000 people were waiting for an NHS neurology appointment, and more than 55,000 people were waiting for NHS neurosurgery.

**“It’s been 18 months since my referral to a Neurology service and over two and a half years since being referred from the hospital, I’ve had no diagnosis or treatment pathway since having an MRI scan and finding out I had a brain injury.”**

People are feeling abandoned – many people told us they had been referred for a service, but were not sure how long they were likely to wait for. 44% of respondents said they had not received support whilst waiting. Just 5% felt communications from NHS services whilst waiting for care were good.

**“It’s been 4 years and the nerve damage is increasing, I’m concerned about how to keep working...The impact on my life has been massive. My quality of life is poor.”**

### Specialist care too far

**“It’s over an hour’s drive away, I don’t travel well or without pain now, I’m also just diagnosed with cholangitis so am feeling sick most the time too.”**

Care should be delivered as close to home as possible. Specialist input should be available in every region of the country, but is often out of reach. Many people shared with us this month the agonizing journey they have to undertake to see their specialist, often at great personal cost.

### **Turning to private health care**

As a result, having to wait for a long time for support, people are turning to private healthcare, further widening health inequalities.

**“I was told it would take at least three years on a waiting list to get a full diagnosis on the NHS. As a result I paid for private diagnosis.”**

**“I am not currently waiting for NHS care as I’ve had to go private in order to get the treatment I need.”**

### **Not everyone experiences poor care**

Importantly, a number of people told us that access to the right care was lifechanging. Some people reported good experiences with the NHS – this begs the question, if we can achieve good care in one part of the country and for some individuals, why not all?

**“It’s been 18 months since my referral to a Neurology service and over two and a half years since being referred from the hospital, I’ve had no diagnosis or treatment pathway since having an MRI scan and finding out I had a brain injury.”**

**“I haven’t had trouble with any of my other appointments though and generally don’t wait very long at all.”**

If you need support, the Brain & Spine Foundation neuroscience nurses are here for you, providing practical and emotional support relating to any neurological condition(s). You can get in touch for free by calling our specialist nurse run helpline on 0808 808 1000 (Mon-Fri, 9am – 4pm) or email [helpline@brainandspine.org.uk](mailto:helpline@brainandspine.org.uk)

Thank you

The Brain & Spine Foundation Team

Georgina Carr, CEO, The Neurological Alliance, England

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## Key Findings

**1,015 responses** were received in March to April 2024.

**118 conditions** were represented. **46%** of people reported **living with more than one condition**. The conditions most often listed were **Functional Neurological Disorder (FND)**, **multiple sclerosis (MS)** and **dystonia**.

**48%** of respondents were **waiting for healthcare** at the time of completing the survey.

**44%** of respondents who were waiting for care said they had **not received any information from the NHS whilst waiting**. People with multiple neurological conditions were most likely to report this.

**34%** of all respondents described **communication** from the NHS whilst waiting for care as **poor**. Just 5% said communication had been good.

**38%** of respondents said that overall, they **experienced good or very good healthcare** in the past eight weeks.

**58%** of respondents said they had at least **one medical appointment** in the eight weeks previous to taking the survey. 22% said they had three or more appointments. Most appointments reported were with a GP (39% of respondents said this).

**53%** said they felt **anxious**, **35%** said they felt **hopeless** – an increase from January/February. Just 14% felt well supported. In parallel, **43% of people said their mental health needs were not being met at all**.



## Qualitative analyses - Recent experiences of waiting for NHS care

### Word cloud



Figure 1: Word cloud showing key words used by respondents related to recent experiences of waiting for NHS care.

### Thematic analysis

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

- Theme 1: Long waiting period
- Theme 2: Fragmented and inefficient healthcare system
  - Difficult to navigate
  - Inconvenience to access healthcare
  - Fragmented system
- Theme 3: Did not receive treatment



- Theme 4: Cancellations
- Theme 5: Unprofessional service providers
- Theme 6: Ineffective treatment
- Theme 7: No response
- Theme 8: Frustration, worry, and feeling abandoned
- Theme 9: Impacts of complications and worse symptoms
- Theme 10: Went to private care
- Theme 11: Good experience

### **Theme 1: Long waiting period**

One main recurring theme reported by the respondents is the long waiting period they had to endure.

“It’s been 18 months since my referral to Neurology at Sheffield Hospital and over two and a half years since being referred from Lincoln Hospital, I’ve had no diagnosis or treatment pathway since having an MRI scan and finding out I had a brain injury.”

“First neurologist local hospital, had 12month wait for follow up appointments, second referral to specialist in London took 10 months...”

“I was told that there was a 51 week waiting list, on the 51st week I received a letter saying I would have a telephone appointment, that happened in December 2023, the appointment lasted 2minutes as he said he would need to see me face to face. He did say it would be about 2 to 3 months time, I have already gone over the 3 months wait. In the meantime I am getting no help from anybody.”

### **Theme 2: Fragmented and inefficient healthcare system**

The respondents also faced multiple difficulties in accessing treatment due to the fragmented and inefficient healthcare system.

#### **Difficult to navigate**

It has been reported that the healthcare system was difficult to navigate, especially given the neurological conditions that the respondents have.

“...my appointment...had been cancelled...they said it was probably a computer error, I asked when it would be rebooked for as I am severely disabled, getting anywhere is a complex military operation and I need plenty of notice, they just said that I would get a letter...”

These are not my only appointments and also not the only cancellations I have to deal with and given the damage to my brain I find it very difficult to keep up and get really anxious that I might have missed an appointment because I can't keep up with what is where"

### Inconvenience to access healthcare

It was also inconvenient for the respondents to access healthcare. For example, travel distance was too far.

"I had a letter with a booking reference number to book my appointment for multi Disciplinary pain management team. Went on NHS app to do it and it wouldn't let me as no appointments available in the next 6 months."

"Waiting for an appointment to see neurology regarding my IIH as I move out of area of my last hospital 6 months ago. Too far to travel as its 2 hours away."

"It's over an hour's drive away, I don't travel well or without pain now, I'm also just diagnosed with cholangitis so am feeling sick most the time too."

### Fragmented system

Some respondents also noticed that the system is fragmented as the system is divided into separate parts or silos that do not work together cohesively.

"Communication between medics and departments and admin. is chaotic and contradictory. When I ask simple questions, no-one can answer them."

"I was seen recently in Neurology and thought this appointment was a follow up from my admission in January 2023 but I was wrong. The Dr's exact words were "I've no idea why you're here". He checked who had referred me and discovered it was a follow up from the Neurology Recall from 6 years previously!!"

"I was given medication by the neurologist, but my GP wasn't informed before they ran out and I haven't been able to get more."

### Theme 3: Did not receive treatment

It was reported that some respondents did not receive treatment they wanted. For example, they were denied treatment or the treatment was not available.

"The neurosurgeon refused to do a DNRB because he said there was no target, I said there's the TC, he said no target that we'd do anything with!"

"Diagnosed 8 years ago by GP but told no where to refer me too and offered nothing other than basic bloods."

"Rejected by several more hospitals as not in area, waiting lists too long, age."

#### **Theme 4: Cancellations**

Some respondents have had their healthcare appointments cancelled.

“I have repeatedly had cancellations due to staff shortages, etc”

“An appointment was scheduled for the 02 Apr 2024, this was cancelled and I’m back waiting for another appointment.”

“Initial cancellation in July last year due to staff shortages cancelled just 2 days before appointment so I still had to pay the disabled taxi company as too late to cancel booking, the second cancellation was in November due to “IT” issues, the third cancellation in Feb 2024 due to strikes.”

#### **Theme 5: Unprofessional service providers**

Some respondents have reported encountering unprofessional service providers.

“The physiotherapist did not believe how bad the pain in my head and neck was and yanked my head round causing pain in my neck, saying movement in my neck was ok.”

“In fact when I first raised issue with GP I was laughed at, despite having had head trauma in a car accident and a diagnosed csf leak. Doctors are generally useless when it comes to csf leak.”

“10 years of my life wasted because of prejudiced GP knowing nothing about neurodevelopmental and neurological conditions and considering women “attention seekers” and coercing me to take harmful, highly addictive SNRIs instead.”

#### **Theme 6: Ineffective treatment**

- On some occasions, even if respondents received treatments, the treatments did not work or worsened their conditions.

“I had a nerve biopsy carried out in October 2022, which went wrong and then the stitches were removed causing it to be an open wound.”

“Have been on antivirals for Flu for over a year. Expressed not working at last appointment so dose doubled.”

“Try more medication with horrid side effects and doesn’t really work”

#### **Theme 7: No response**

Even though the respondents reached out to the healthcare service providers, they were not contacted back and there was no response or follow-up.

“I have not heard anything at all since I was diagnosed about when to expect my follow up appointment.”

“I sometimes receive verbal information that I have been referred, or am on a waiting list. Sometimes this information is in a brief note to my GP, but then everything goes silent, and chasing up further information usually results in me going round in circles and getting nowhere”

“No follow up with the neurologist has been booked”

### **Theme 8: Frustration, worry, and feeling abandoned**

Due to the long waiting time and other problems faced by the respondents in accessing NHS healthcare, frustrations, worry, and feeling of abandonment were expressed.

“Sorry, it just frustrates me knowing how it can help me, for years, only to be denied it when needed most.”

“Very little can be done for my Chronic Fatigue Syndrome so have been left to deal with on my own for over a decade.”

“I felt initially like I’d been hung out to dry, like no one was bothered as I’m 75.”

“The waiting times are unacceptable and cause significant mental and physical health decline.”

“It’s worrying when I don’t know if my symptoms are caused by Chiari malformation or if there’s something else going on. I’m worried about my mental function deteriorating, and I rely on it for my work because I can’t do physical work. It’s frightening getting hallucinations and not knowing why - psychiatrists already ruled out it being caused by psychosis etc...”

### **Theme 9: Impacts of complications and worse symptoms**

The long waiting time and other problems faced by the respondents in accessing NHS healthcare have also negatively impacted their quality of life and physical health, resulting in more complications and worse symptoms.

“I’ve been waiting bedbound for 2 years just for a repeat scan to try find the site of my suspected spinal CSF leak. Any amount of time bedbound is hard, but this last 2 years has been especially tough; my health is declining after >4 years in bed.”

“It’s been 4 years and the nerve damage is increasing, I’m concerned about how to keep working...The impact on my life has been massive. My quality of life is poor.”

“While I wait my symptoms are getting worse.”

“I am left in limbo. I had a stroke. It’s affect my life in so many ways. I live with reduced mobility and a great deal of pain.”

### **Theme 10: Went to private care**

As a result of the long waiting time, some respondents resorted going to private care.

“After being diagnosed with OT after begging my GP to go private, I obviously saw a Consultant as I went private quickly and my diagnosis was confirmed.”

“I was told it would take at least three years on a waiting list to get a full diagnosis on the NHS. As a result I paid for private diagnosis.”

“I am not currently waiting for NHS care as I’ve had to go private in order to get the treatment I need.”

### **Theme 11: Good experience**

Despite the negative experiences listed above, some respondents have reported good experience with the NHS.

“Since being referred to the specialist Sheffield Ataxia unit, the appointments with the consultant, PET and CAT scans have been timely and informative with regular contact with the neuro nurses (via telephone).”

“I haven’t had trouble with any of my other appointments though and generally don’t wait very long at all.”

“The care and service I receive at The Royal London Hospital, part of BARTS NHS Trust is 1st class.”

## Experience with waiting for NHS appointment/treatment

### Whether waiting for NHS appointment/treatment

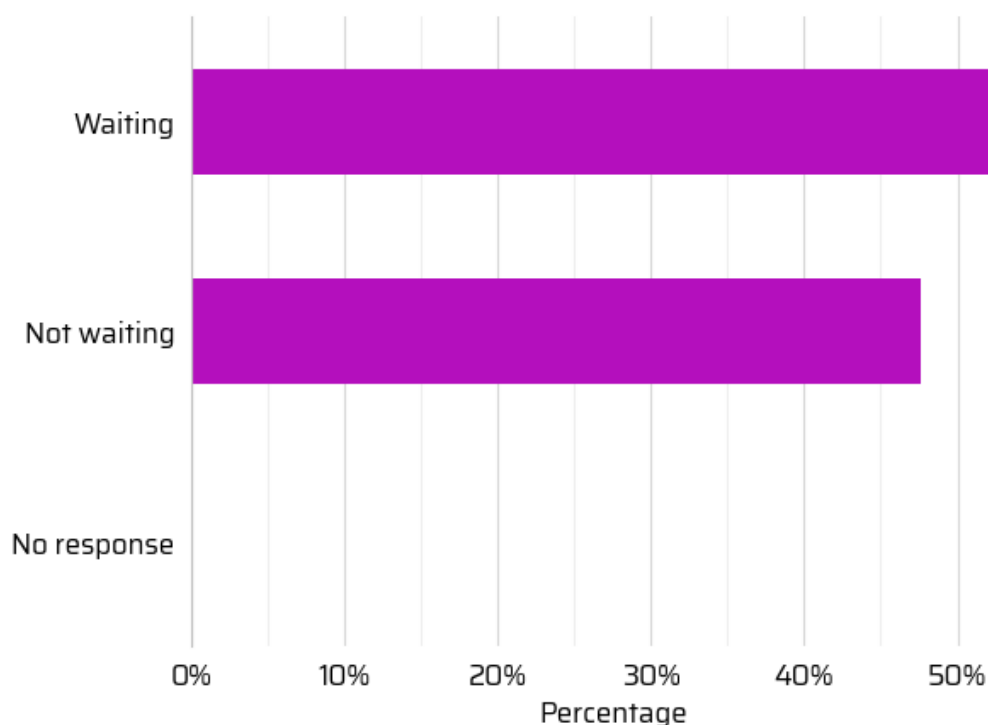


Figure 1 Whether waiting for NHS appointment/treatment

Table 1 Whether waiting for NHS appointment/treatment

Whether waiting	Respondents	Percentage
Waiting	532	52.41
Not waiting	483	47.59
No response	0	0.0

### Whether waiting for NHS appointment/treatment: with vs without multiple neurological conditions

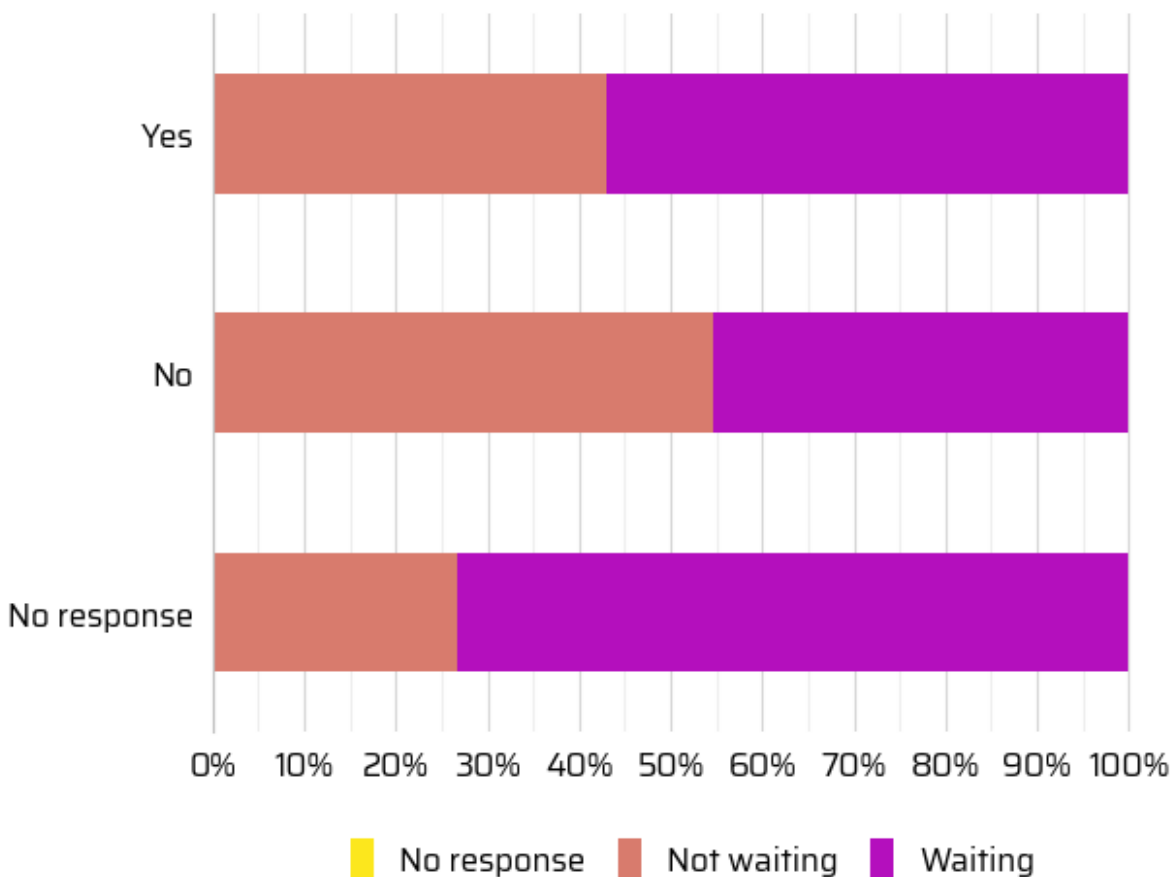


Figure 2 Whether waiting for NHS appointment/treatment among people with vs without multiple neurological conditions

Table 2 Whether waiting for NHS appointment/treatment among people with vs without multiple neurological conditions

Multiple neurological conditions	Whether waiting	Respondents	Percentage
Yes	Waiting	267	57.05
	Not waiting	201	42.95
	No response	0	0.0
No	Waiting	221	45.38



	Not waiting	266	54.62
	No response	0	0.0
	Waiting	44	73.33
<b>No response</b>	Not waiting	16	26.67
	No response	0	0.0

### Whether received information from the NHS on available support while waiting

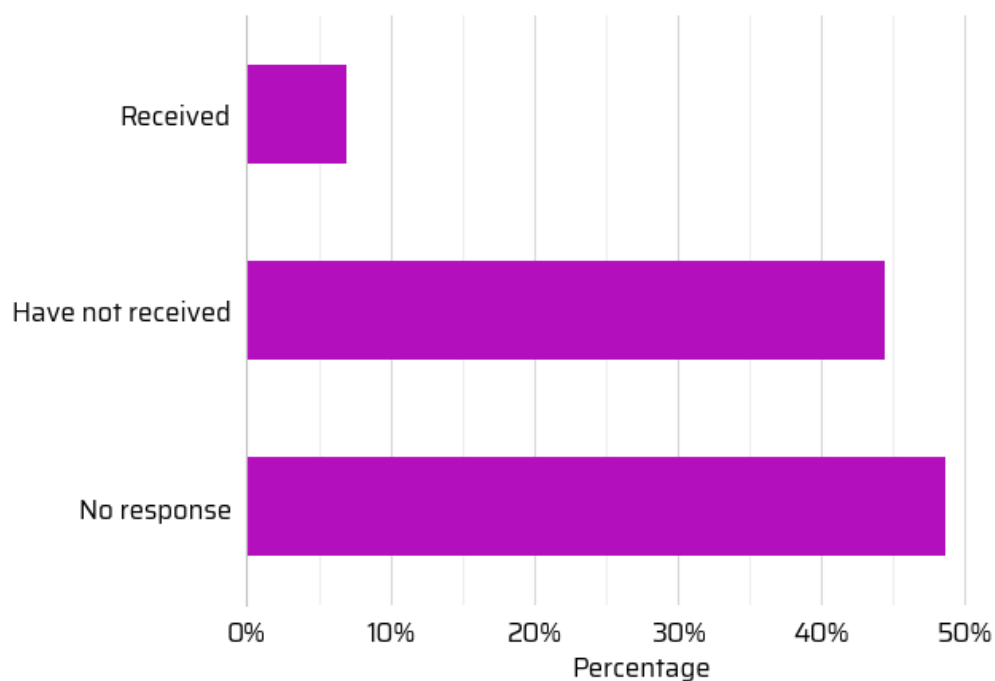


Figure 3 Whether received information from the NHS on available support while waiting

Table 3 Whether received information from the NHS on available support while waiting

Whether received information	Respondents	Percentage
Received	70	6.9
Have not received	451	44.43

No response 494 48.67

**Whether received information from the NHS on available support while waiting: with vs without multiple neurological conditions**

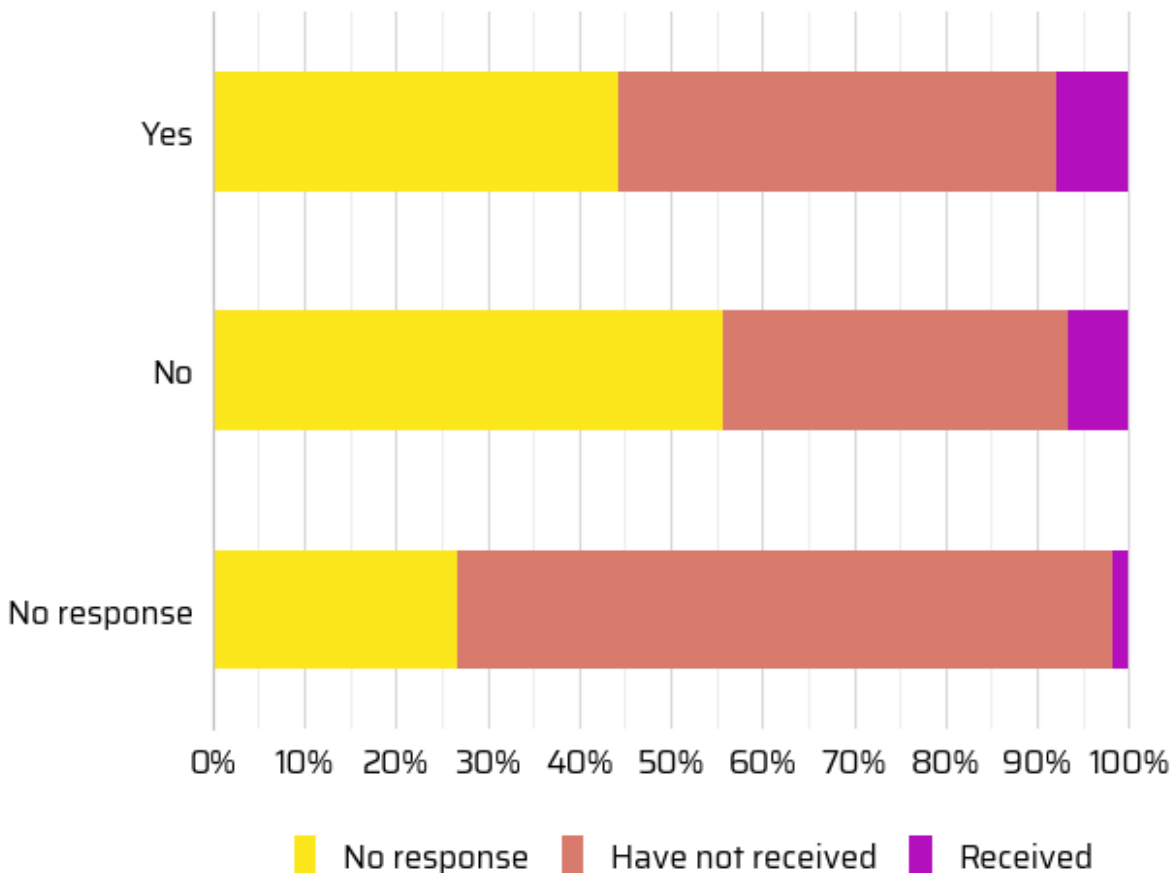


Figure 4 Whether received information from the NHS on available support while waiting among people with vs without multiple neurological conditions

Table 4 Whether received information from the NHS on available support while waiting among people with vs without multiple neurological conditions

Multiple neurological conditions	Whether received information	Respondents	Percentage
Yes	Received	37	7.91

	Have not received	224	47.86
	No response	207	44.23
	Received	32	6.57
<b>No</b>	Have not received	184	37.78
	No response	271	55.65
	Received	1	1.67
<b>No response</b>	Have not received	43	71.67
	No response	16	26.67

### Quality of communications from the NHS while waiting

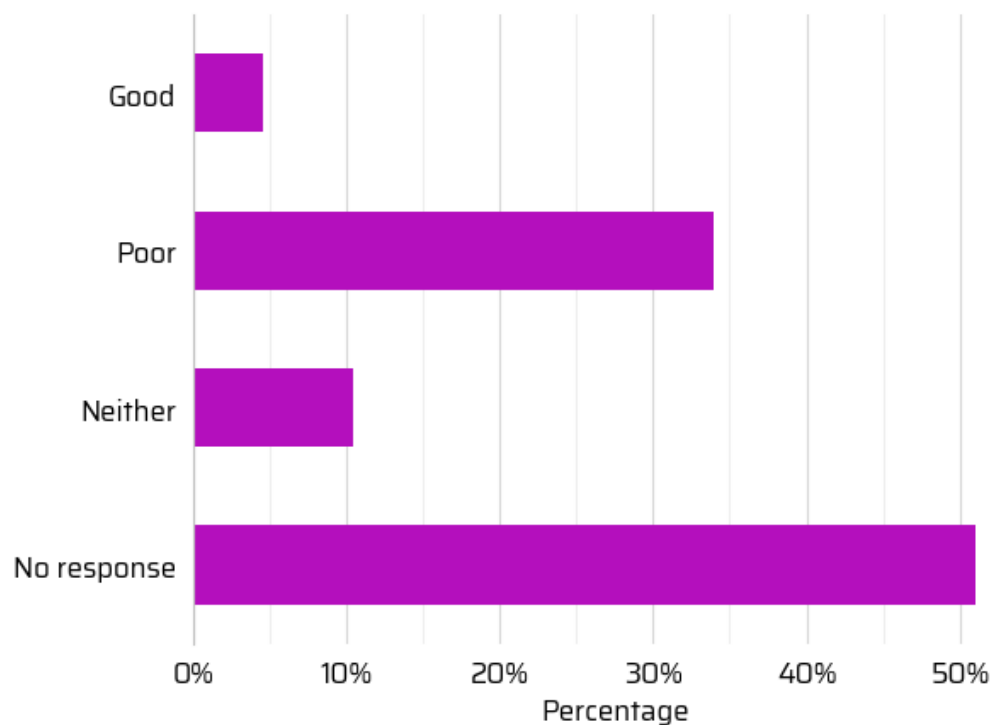


Figure 5 Quality of communications from the NHS while waiting

Table 5 Quality of communications from the NHS while waiting

Quality	Respondents	Percentage
Good	46	4.53
Poor	345	33.99
Neither	106	10.44
No response	518	51.03

**Quality of communications from the NHS while waiting: with vs without multiple neurological conditions**

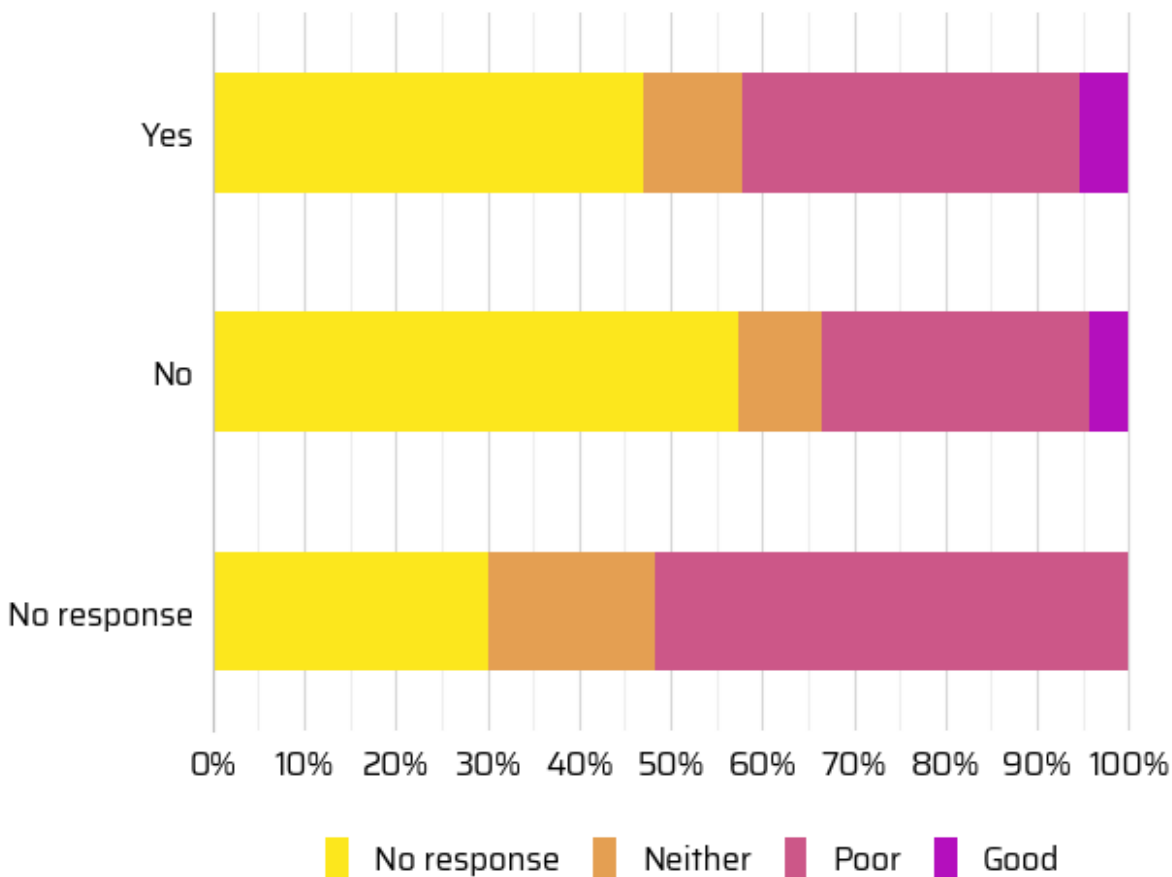


Figure 6 Quality of communications from the NHS while waiting among people with vs without multiple neurological conditions

Table 6 Quality of communications from the NHS while waiting among people with vs without multiple neurological conditions

<b>Multiple neurological conditions</b>	<b>Quality</b>	<b>Respondents</b>	<b>Percentage</b>
<b>Yes</b>	Good	25	5.34
	Poor	172	36.75
	Neither	51	10.9
	No response	220	47.01
<b>No</b>	Good	21	4.31
	Poor	142	29.16
	Neither	44	9.03
	No response	280	57.49
<b>No response</b>	Good	0	0.0
	Poor	31	51.67
	Neither	11	18.33
	No response	18	30.0

## Medical appointments

### Access to medical appointments in the last eight weeks

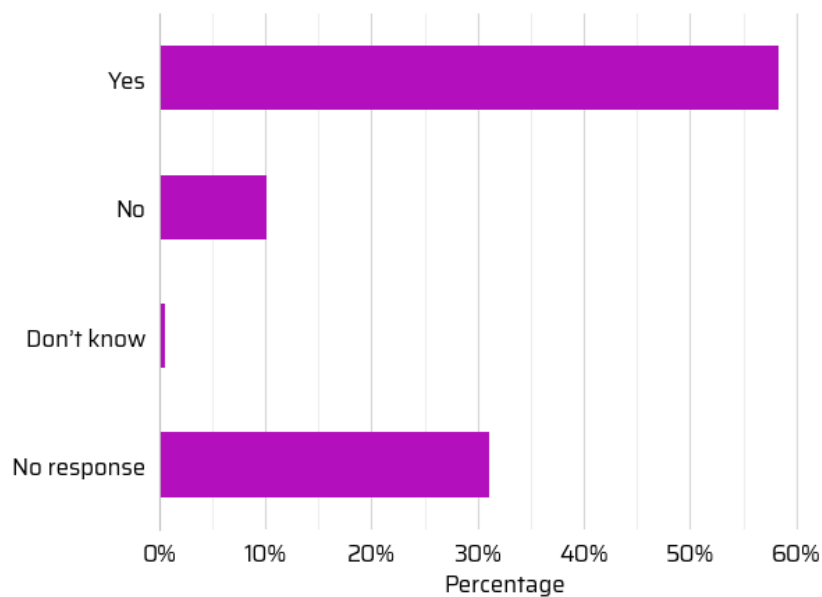


Figure 7 Access to medical appointments in the last eight weeks

Table 7 Access to medical appointments in the last eight weeks

Appointments	Respondents	Percentage
Yes	592	58.33
No	102	10.05
Don't know	5	0.49
No response	316	31.13

## Number of medical appointments

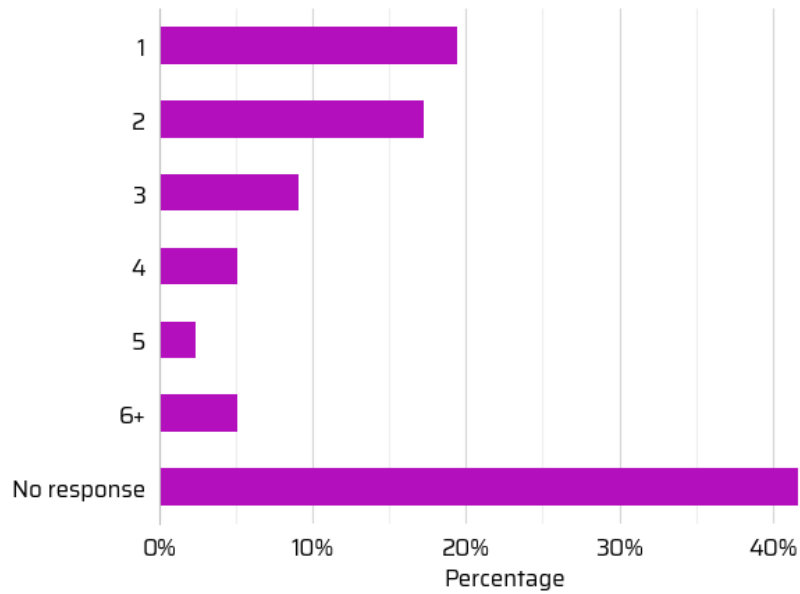


Figure 8 Number of medical appointments

Table 8 Number of medical appointments

Number of appointments	Respondents	Percentage
<b>1</b>	197	19.41
<b>2</b>	175	17.24
<b>3</b>	92	9.06
<b>4</b>	52	5.12
<b>5</b>	24	2.36
<b>6+</b>	52	5.12
<b>No response</b>	423	41.67



## Helpfulness of medical appointments

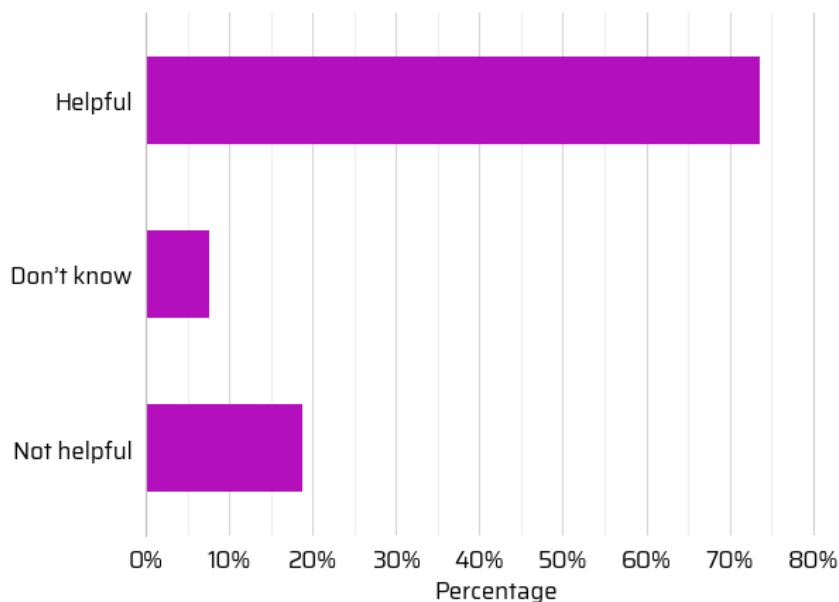


Figure 9 Helpfulness of medical appointments held in the last eight weeks

Table 9 Helpfulness of medical appointments held in the last eight weeks

Helpfulness	Respondents	Percentage
Helpful	1090	73.65
Don't know	113	7.64
Not helpful	277	18.72

Note: Each respondent may have zero, one, or multiple appointments, so the total number of appointments may not match the total number of respondents. The percentages provided indicate the proportion of responses relative to the total number of responses (i.e. appointments) to this question.

## Specialty of medical appointments

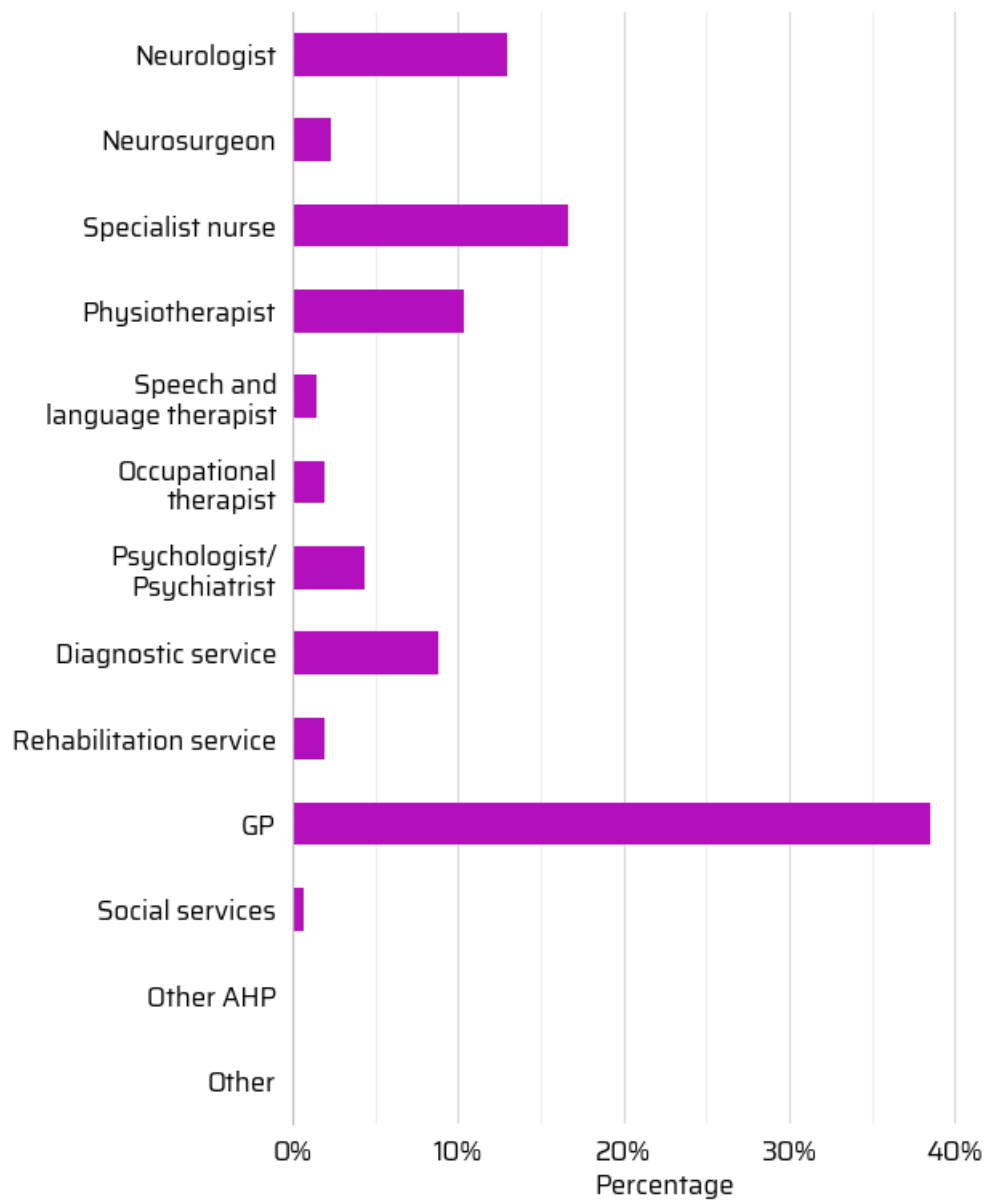


Figure 10 Speciality of the medical appointments held in the last eight weeks

Table 10 Speciality of the medical appointments held in the last eight weeks

Specialty	Respondents	Percentage
Neurologist	156	13.03
Neurosurgeon	28	2.34
Specialist nurse	199	16.62

<b>Physiotherapist</b>	124	10.36
<b>Speech and language therapist</b>	17	1.42
<b>Occupational therapist</b>	23	1.92
<b>Psychologist/ Psychiatrist</b>	52	4.34
<b>Diagnostic service</b>	106	8.86
<b>Rehabilitation service</b>	23	1.92
<b>GP</b>	461	38.51
<b>Social services</b>	8	0.67
<b>Other AHP</b>	0	0.0
<b>Other</b>	0	0.0

Note: Each respondent may have zero, one, or multiple appointments, so the total number of appointments may not match the total number of respondents. The percentages provided indicate the proportion of responses relative to the total number of responses (i.e. appointments) to this question.

### Mode of medical appointments completed

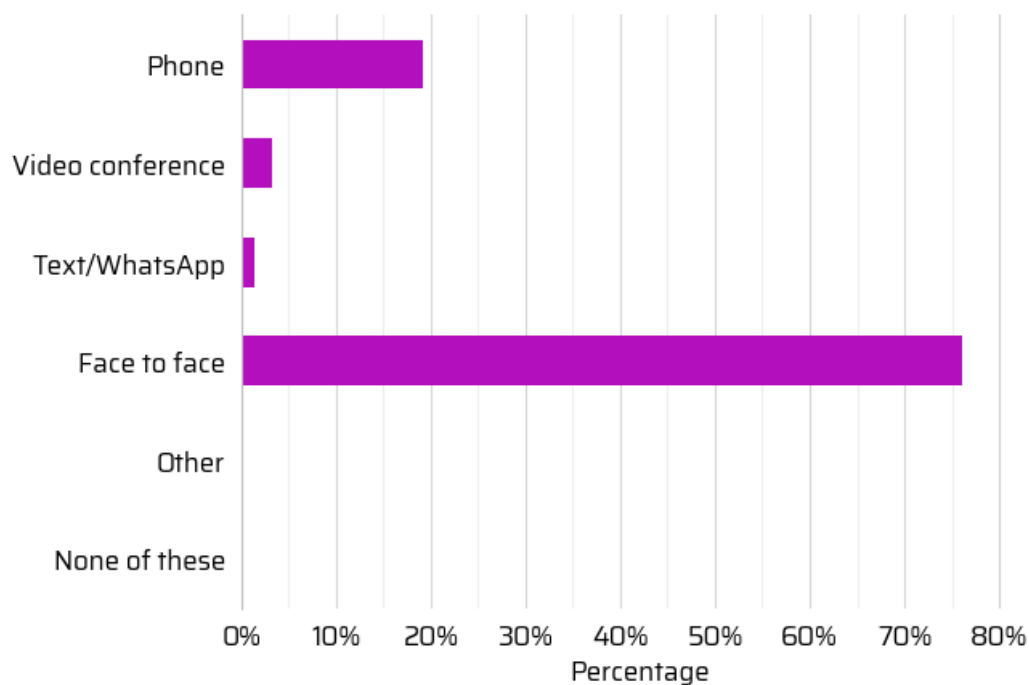


Figure 11 Mode of medical appointments completed in the last eight weeks

Table 11 Mode of medical appointments completed in the last eight weeks

Mode	Respondents	Percentage
Phone	278	19.11
Video conference	48	3.3
Text/WhatsApp	21	1.44
Face to face	1108	76.15
Other	0	0.0
None of these	0	0.0

Note: Each respondent may have zero, one, or multiple appointments, so the total number of appointments may not match the total number of respondents. The percentages provided indicate the proportion of responses relative to the total number of responses (i.e. appointments) to this question.

## Mental health

### Current feelings

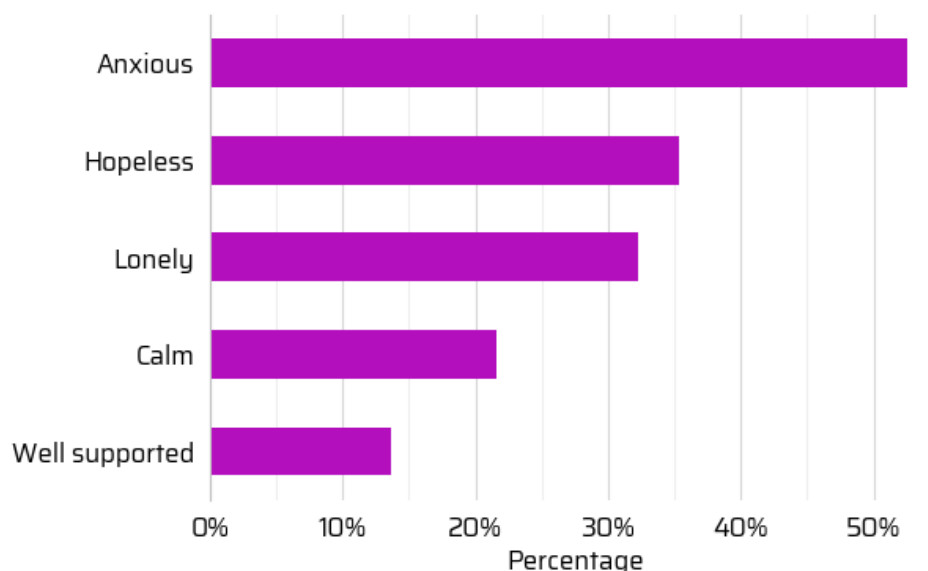


Figure 12 Feelings of the respondents at the time of the survey

Table 12 Feelings of the respondents at the time of the survey

Feelings	Respondents	Percentage
<b>Anxious</b>	533	52.51
<b>Hopeless</b>	359	35.37
<b>Lonely</b>	327	32.22
<b>Calm</b>	219	21.58
<b>Well supported</b>	139	13.69

Note: A single respondent may have selected multiple options for this question, so the total number of responses may not add up to the total number of respondents. The percentages provided indicate the proportion of responses relative to the total number of respondents.

### Impact on quality of life

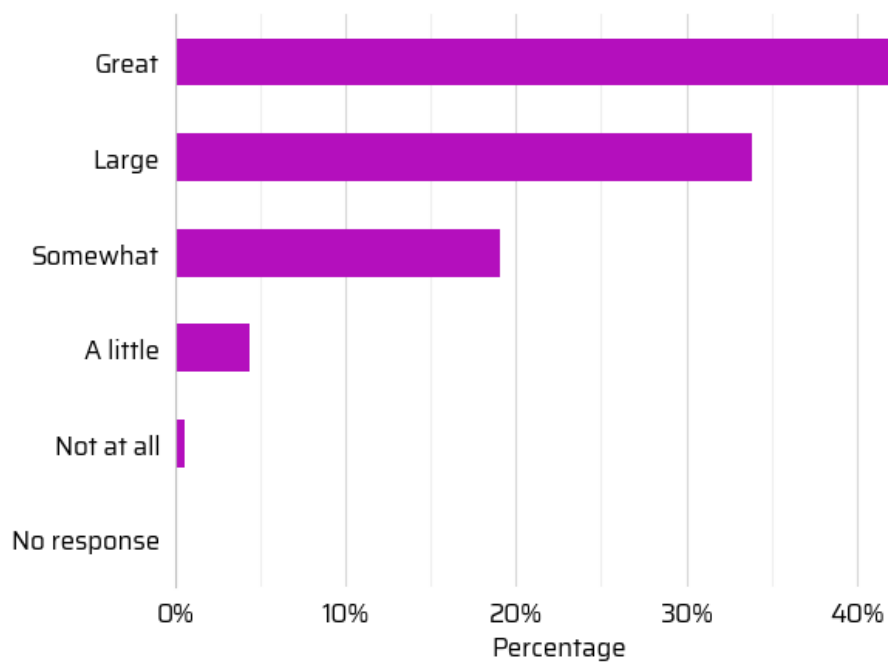


Figure 13 The extent to which neurological conditions affect the quality of life

Table 13 The extent to which neurological conditions affect the quality of life

Impact	Respondents	Percentage
Great	427	42.07
Large	344	33.89
Somewhat	194	19.11
A little	44	4.33
Not at all	6	0.59
No response	0	0.0

### Extent mental health needs were met

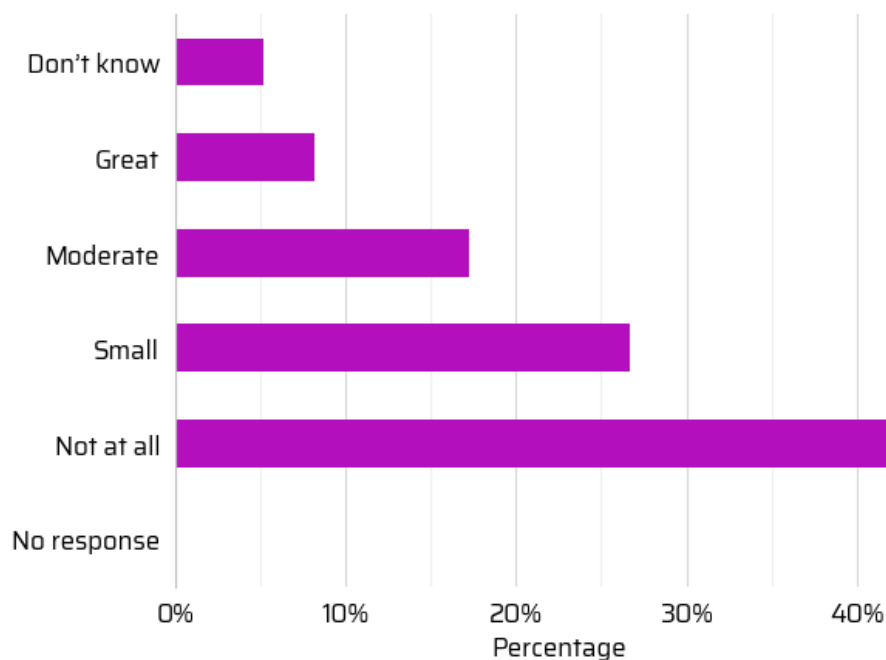


Figure 14 The extent to which respondents' mental health needs were met

Table 14 The extent to which respondents' mental health needs were met

Needs met	Respondents	Percentage
Don't know	53	5.22
Great	83	8.18
Moderate	175	17.24
Small	271	26.7
Not at all	433	42.66
No response	0	0.0



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

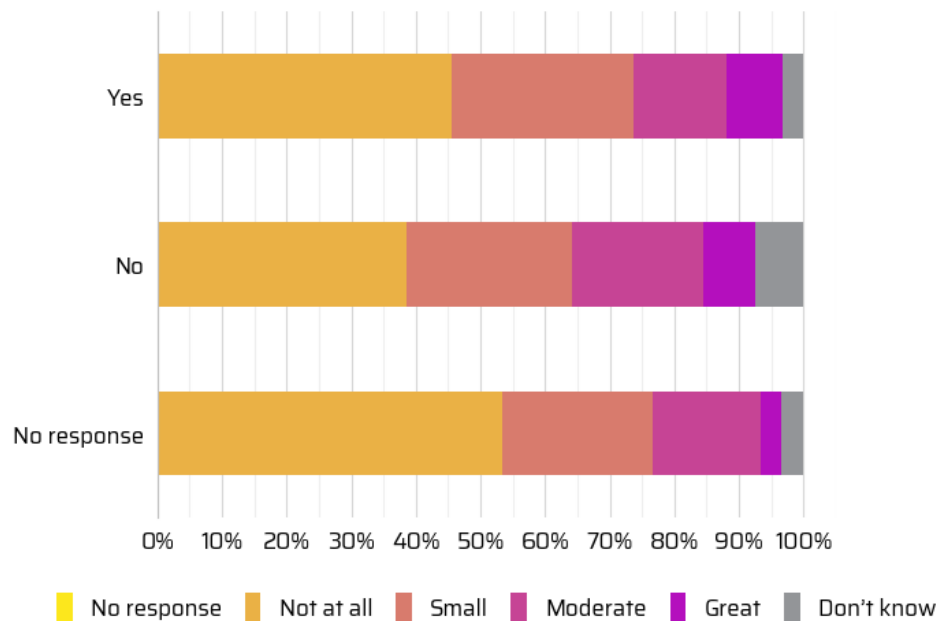


Figure 15 The extent to which respondents' mental health needs were met, broken down by whether diagnosed with multiple neurological conditions

Table 15 The extent to which respondents' mental health needs were met, broken down by whether diagnosed with multiple neurological conditions

Multiple neurological conditions	Needs met	Respondents	Percentage
<b>Yes</b>	Don't know	15	3.21
	Great	41	8.76
	Moderate	67	14.32
	Small	132	28.21
	Not at all	213	45.51
	No response	0	0.0
<b>No</b>	Don't know	36	7.39

	Great	40	8.21
	Moderate	98	20.12
	Small	125	25.67
	Not at all	188	38.6
	No response	0	0.0
<b>No response</b>	Don't know	2	3.33
	Great	2	3.33
	Moderate	10	16.67
	Small	14	23.33
	Not at all	32	53.33
	No response	0	0.0

### Extent mental health needs were met by age groups

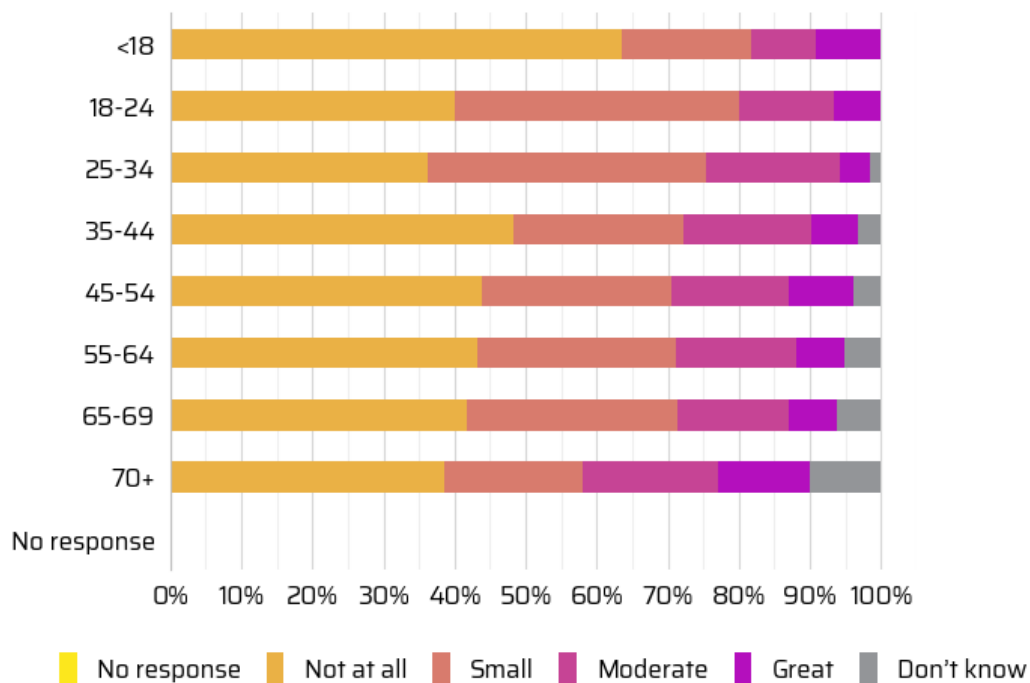


Figure 16 The extent to which respondents' mental health needs were met, broken down by age group

Table 16 The extent to which respondents' mental health needs were met, broken down by age group

Age	Needs met	Respondents	Percentage
<18	Don't know	0	0.0
	Great	1	9.09
	Moderate	1	9.09
	Small	2	18.18
	Not at all	7	63.64
	No response	0	0.0
18-24	Don't know	0	0.0
	Great	1	6.67
	Moderate	2	13.33

	Small	6	40.0
	Not at all	6	40.0
	No response	0	0.0
	Don't know	1	1.45
	Great	3	4.35
	Moderate	13	18.84
<b>25-34</b>	Small	27	39.13
	Not at all	25	36.23
	No response	0	0.0
	Don't know	4	3.28
	Great	8	6.56
	Moderate	22	18.03
<b>35-44</b>	Small	29	23.77
	Not at all	59	48.36
	No response	0	0.0
	Don't know	8	3.81
	Great	19	9.05
	Moderate	35	16.67
<b>45-54</b>	Small	56	26.67
	Not at all	92	43.81
	No response	0	0.0

	Don't know	15	5.1
	Great	20	6.8
	Moderate	50	17.01
<b>55-64</b>	Small	82	27.89
	Not at all	127	43.2
	No response	0	0.0
	Don't know	7	6.09
	Great	8	6.96
	Moderate	18	15.65
<b>65-69</b>	Small	34	29.57
	Not at all	48	41.74
	No response	0	0.0
	Don't know	18	10.06
	Great	23	12.85
	Moderate	34	18.99
<b>70+</b>	Small	35	19.55
	Not at all	69	38.55
	No response	0	0.0
	Don't know	0	0.0
<b>No response</b>	Great	0	0.0
	Moderate	0	0.0

Small	0	0.0
Not at all	0	0.0
No response	0	0.0

### Extent mental health needs were met by gender

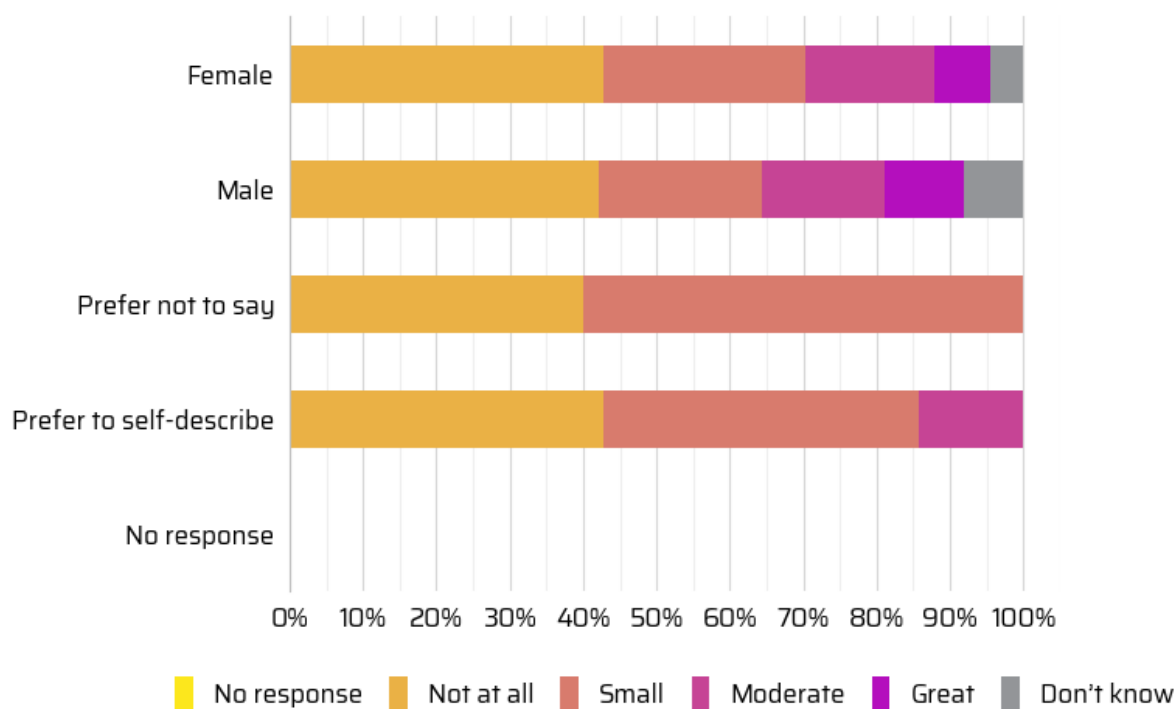


Figure 17 The extent to which respondents' mental health needs were met, broken down by gender

Table 17 The extent to which respondents' mental health needs were met, broken down by gender

Gender	Needs met	Respondents	Percentage
Female	Don't know	36	4.55
	Great	60	7.58
	Moderate	139	17.55
	Small	218	27.53

	Not at all	339	42.8
	No response	0	0.0
	Don't know	17	8.06
	Great	23	10.9
	Moderate	35	16.59
<b>Male</b>	Small	47	22.27
	Not at all	89	42.18
	No response	0	0.0
	Don't know	0	0.0
	Great	0	0.0
	Moderate	0	0.0
<b>Prefer not to say</b>	Small	3	60.0
	Not at all	2	40.0
	No response	0	0.0
	Don't know	0	0.0
	Great	0	0.0
	Moderate	1	14.29
<b>Prefer to self-describe</b>	Small	3	42.86
	Not at all	3	42.86
	No response	0	0.0
<b>No response</b>	Don't know	0	0.0

Great	0	0.0
Moderate	0	0.0
Small	0	0.0
Not at all	0	0.0
No response	0	0.0

### Extent mental health needs were met by employment status

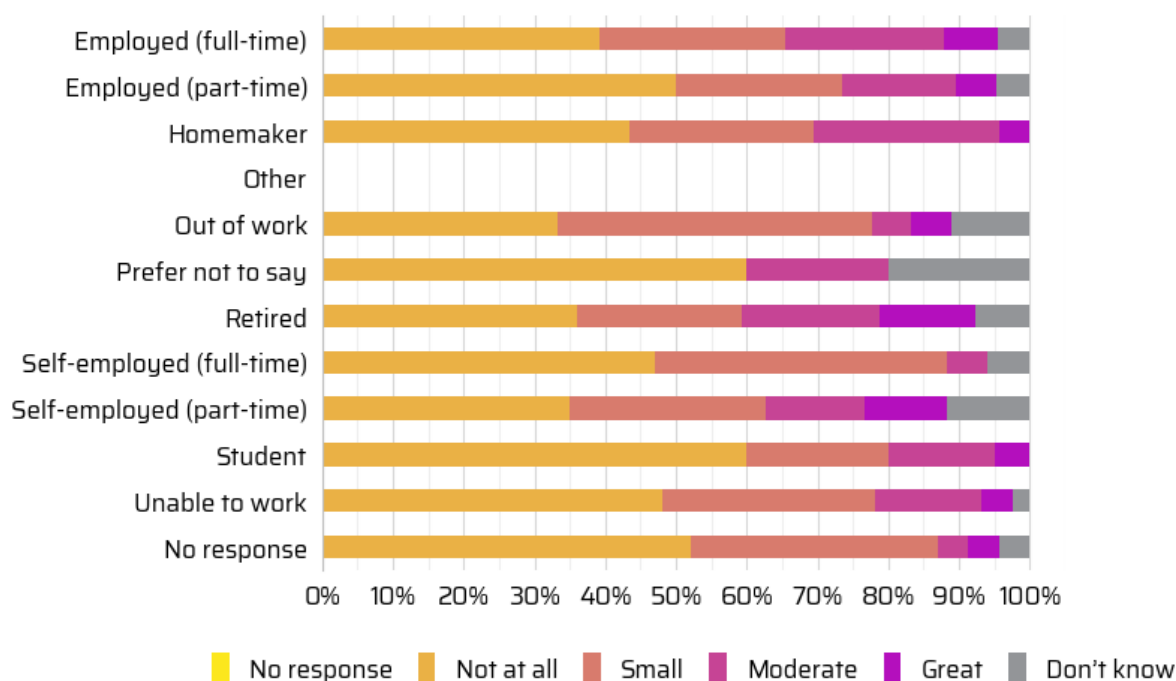


Figure 18 The extent to which respondents' mental health needs were met, broken down by employment status

Table 18 The extent to which respondents' mental health needs were met, broken down by employment status

Employment status	Needs met	Respondents	Percentage
Employed (full-time)	Don't know	6	4.51
	Great	10	7.52



	Moderate	30	22.56
	Small	35	26.32
	Not at all	52	39.1
	No response	0	0.0
	Don't know	5	4.72
	Great	6	5.66
<b>Employed (part-time)</b>	Moderate	17	16.04
	Small	25	23.58
	Not at all	53	50.0
	No response	0	0.0
	Don't know	0	0.0
	Great	1	4.35
<b>Homemaker</b>	Moderate	6	26.09
	Small	6	26.09
	Not at all	10	43.48
	No response	0	0.0
	Don't know	0	0.0
	Great	0	0.0
<b>Other</b>	Moderate	0	0.0
	Small	0	0.0
	Not at all	0	0.0

	No response	0	0.0
	Don't know	2	11.11
<b>Out of work</b>	Great	1	5.56
	Moderate	1	5.56
	Small	8	44.44
	Not at all	6	33.33
	No response	0	0.0
		Don't know	1
<b>Prefer not to say</b>	Great	0	0.0
	Moderate	1	20.0
	Small	0	0.0
	Not at all	3	60.0
	No response	0	0.0
<b>Retired</b>	Don't know	25	7.58
	Great	45	13.64
	Moderate	64	19.39
	Small	77	23.33
	Not at all	119	36.06
	No response	0	0.0
<b>Self-employed (full-time)</b>	Don't know	1	5.88
	Great	0	0.0

	Moderate	1	5.88
	Small	7	41.18
	Not at all	8	47.06
	No response	0	0.0
	Don't know	5	11.63
	Great	5	11.63
<b>Self-employed (part-time)</b>	Moderate	6	13.95
	Small	12	27.91
	Not at all	15	34.88
	No response	0	0.0
	Don't know	0	0.0
	Great	1	5.0
	Moderate	3	15.0
<b>Student</b>	Small	4	20.0
	Not at all	12	60.0
	No response	0	0.0
	Don't know	7	2.36
	Great	13	4.38
<b>Unable to work</b>	Moderate	45	15.15
	Small	89	29.97
	Not at all	143	48.15

<b>No response</b>	No response	0	0.0
	Don't know	1	4.35
	Great	1	4.35
	Moderate	1	4.35
	Small	8	34.78
	Not at all	12	52.17
	No response	0	0.0

### Extent mental health needs were met by number of dependents

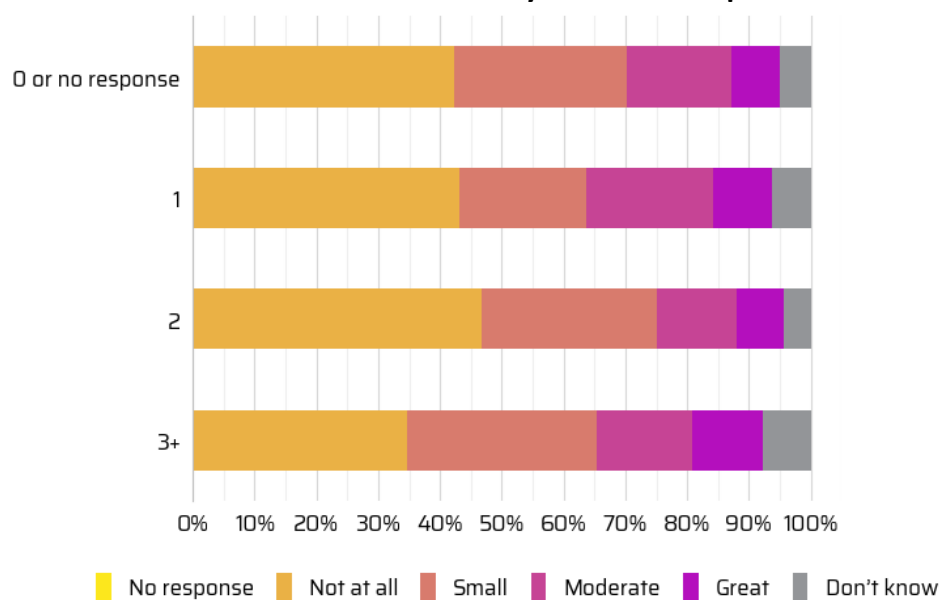


Figure 19 The extent to which respondents' mental health needs were met, broken down by number of dependents

Table 19 The extent to which respondents' mental health needs were met, broken down by number of dependents

Number of dependents	Needs met	Respondents	Percentage
<b>0 or no response</b>	Don't know	35	4.95

	Great	55	7.78
	Moderate	120	16.97
	Small	198	28.01
	Not at all	299	42.29
	No response	0	0.0
<b>1</b>	Don't know	12	6.32
	Great	18	9.47
	Moderate	39	20.53
	Small	39	20.53
	Not at all	82	43.16
	No response	0	0.0
<b>2</b>	Don't know	4	4.35
	Great	7	7.61
	Moderate	12	13.04
	Small	26	28.26
	Not at all	43	46.74
<b>3+</b>	No response	0	0.0
	Don't know	2	7.69
	Great	3	11.54
	Moderate	4	15.38
	Small	8	30.77

Not at all	9	34.62
No response	0	0.0

## Frequency NHS A&E/emergency services were sought

### Frequency NHS A&E/emergency services were sought

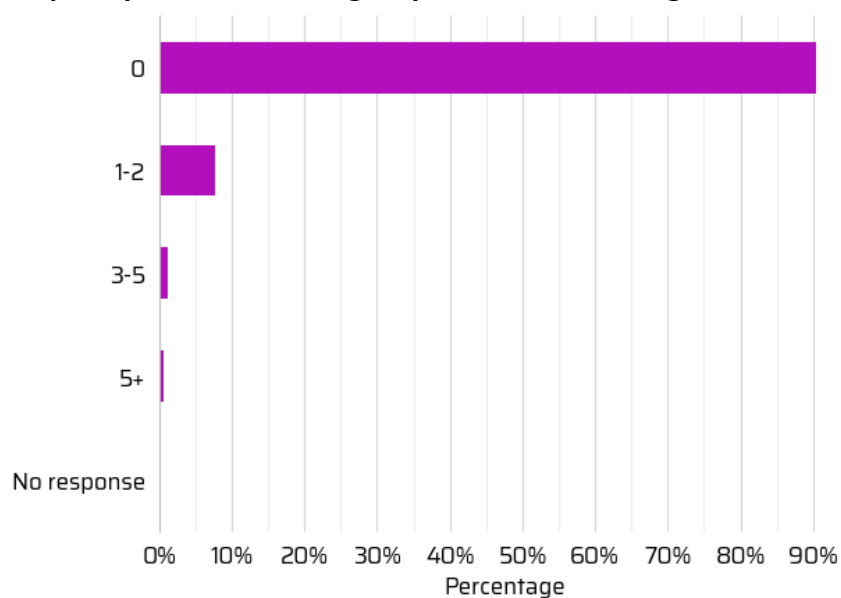


Figure 20 Frequency that NHS A&E/emergency services were sought in the last eight weeks

Table 20 Frequency that NHS A&E/emergency services were sought in the last eight weeks

Frequency	Respondents	Percentage
0	918	90.44
1-2	78	7.68
3-5	12	1.18
5+	7	0.69
No response	0	0.0

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

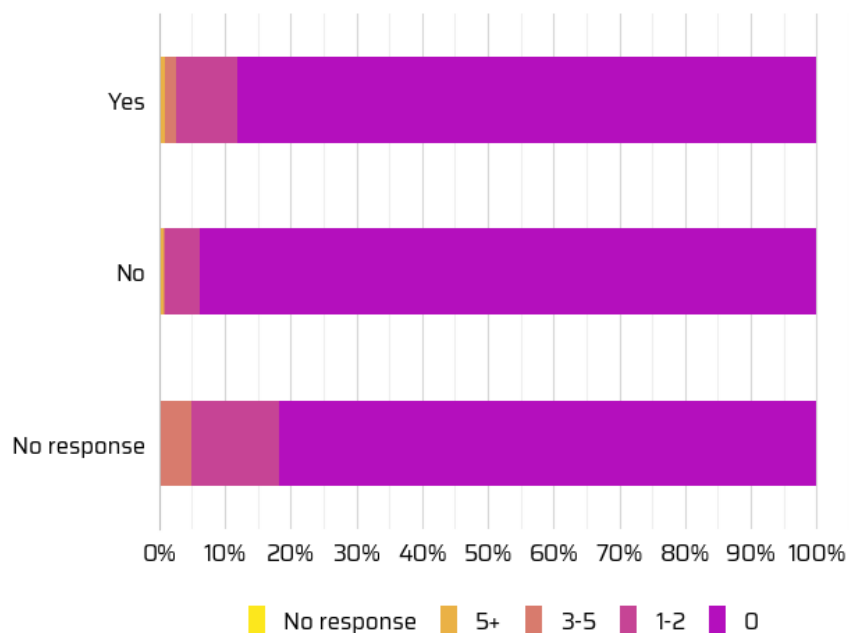


Figure 21 Frequency that NHS A&E/emergency services were sought, broken down by whether diagnosed with multiple neurological conditions

Table 21 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	412	88.03
	1-2	44	9.4
	3-5	8	1.71
	5+	4	0.85
	No response	0	0.0
No	0	457	93.84
	1-2	26	5.34

	3-5	1	0.21
	5+	3	0.62
	No response	0	0.0
<b>No response</b>	0	49	81.67
	1-2	8	13.33
	3-5	3	5.0
	5+	0	0.0
	No response	0	0.0

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

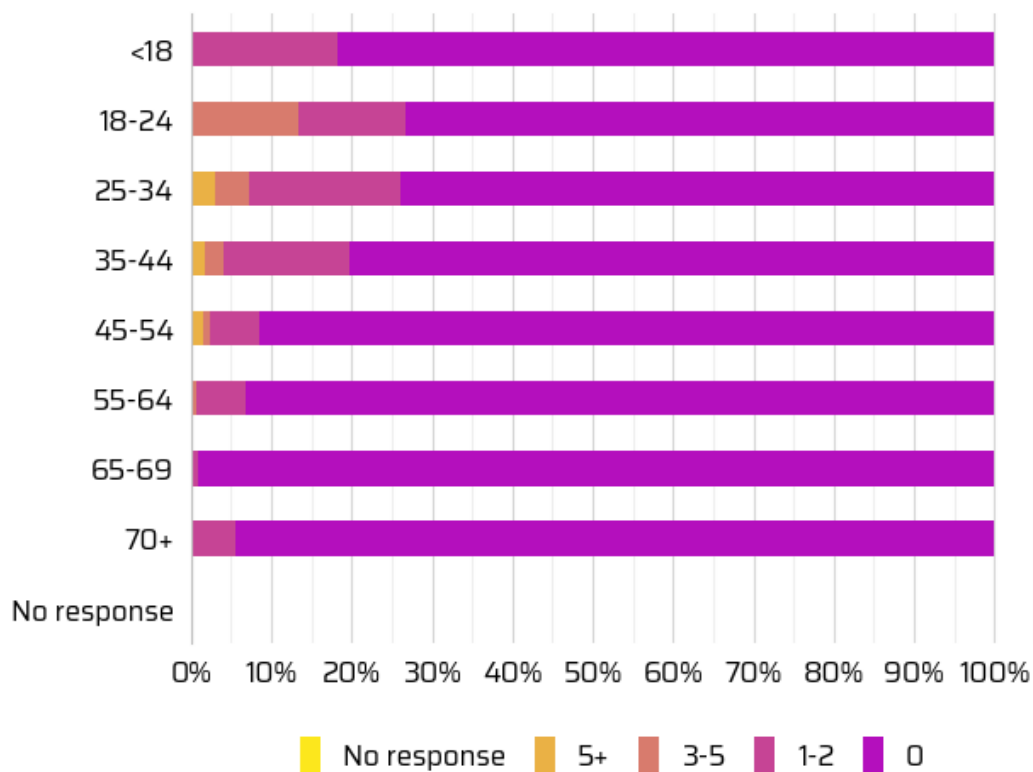


Figure 22 Frequency that NHS A&E/emergency services were sought, broken down by age group



Table 22 Frequency that NHS A&E/emergency services were sought, broken down by age group

Age	Frequency	Respondents	Percentage
<b>&lt;18</b>	0	9	81.82
	1-2	2	18.18
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
<b>18-24</b>	0	11	73.33
	1-2	2	13.33
	3-5	2	13.33
	5+	0	0.0
	No response	0	0.0
<b>25-34</b>	0	51	73.91
	1-2	13	18.84
	3-5	3	4.35
	5+	2	2.9
	No response	0	0.0
<b>35-44</b>	0	98	80.33
	1-2	19	15.57
	3-5	3	2.46
	5+	2	1.64

	No response	0	0.0
	0	192	91.43
	1-2	13	6.19
<b>45-54</b>	3-5	2	0.95
	5+	3	1.43
	No response	0	0.0
	0	274	93.2
	1-2	18	6.12
<b>55-64</b>	3-5	2	0.68
	5+	0	0.0
	No response	0	0.0
	0	114	99.13
	1-2	1	0.87
<b>65-69</b>	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
	0	169	94.41
	1-2	10	5.59
<b>70+</b>	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0

	0	0	0.0
	1-2	0	0.0
<b>No response</b>	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0

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

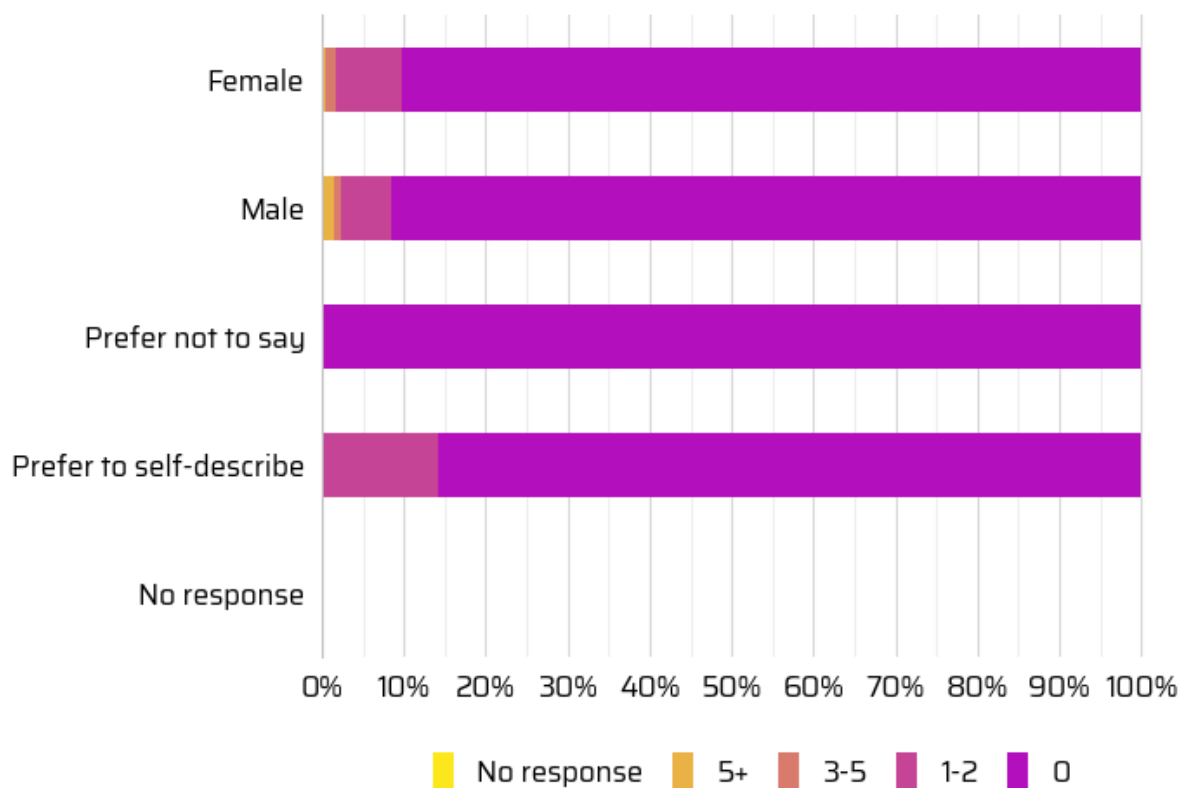


Figure 23 Frequency that NHS A&E/emergency services were sought, broken down by gender

Table 23 Frequency that NHS A&E/emergency services were sought, broken down by gender

Gender	Frequency	Respondents	Percentage
<b>Female</b>	0	714	90.15
	1-2	64	8.08

	3-5	10	1.26
	5+	4	0.51
	No response	0	0.0
	0	193	91.47
	1-2	13	6.16
<b>Male</b>	3-5	2	0.95
	5+	3	1.42
	No response	0	0.0
	0	5	100.0
	1-2	0	0.0
<b>Prefer not to say</b>	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
	0	6	85.71
	1-2	1	14.29
<b>Prefer to self-describe</b>	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
	0	0	0.0
<b>No response</b>	1-2	0	0.0
	3-5	0	0.0

5+	0	0.0
No response	0	0.0

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

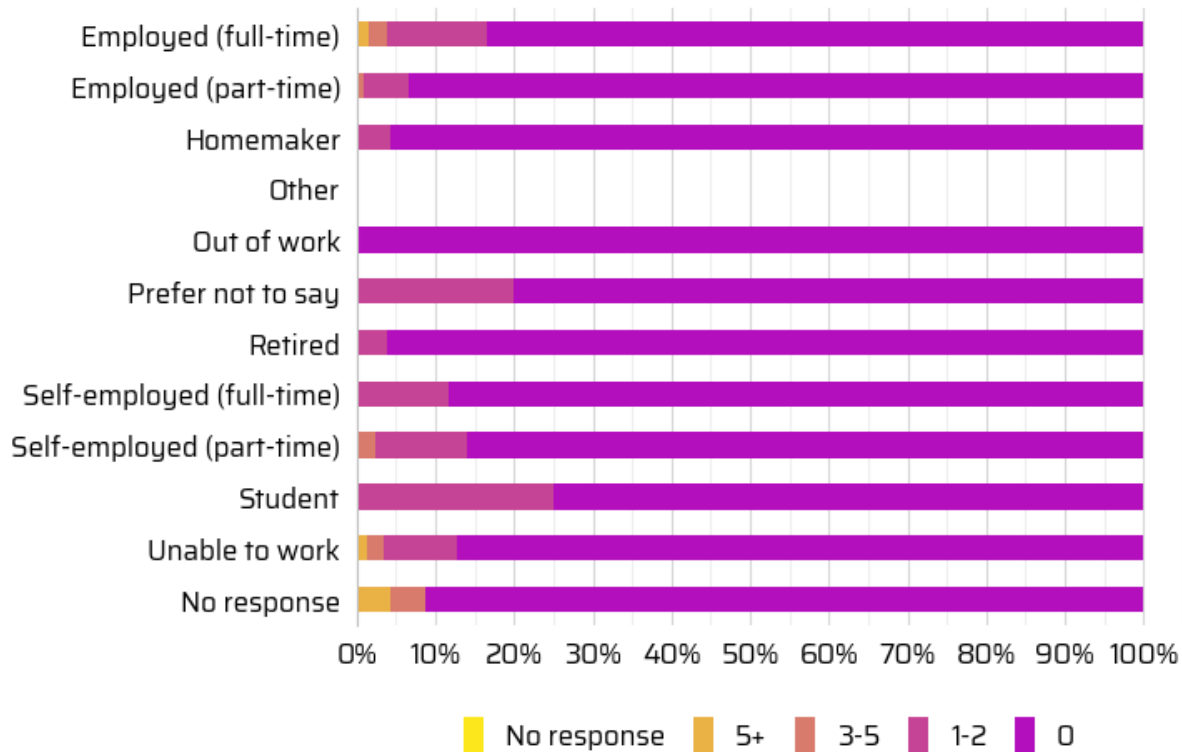


Figure 24 Frequency that NHS A&E/emergency services were sought, broken down by employment status

Table 24 Frequency that NHS A&E/emergency services were sought, broken down by employment status

Employment status	Frequency	Respondents	Percentage
Employed (full-time)	0	111	83.46
	1-2	17	12.78
	3-5	3	2.26
	5+	2	1.5

	No response	0	0.0
<b>Employed (part-time)</b>	0	99	93.4
	1-2	6	5.66
	3-5	1	0.94
	5+	0	0.0
	No response	0	0.0
<b>Homemaker</b>	0	22	95.65
	1-2	1	4.35
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
<b>Other</b>	0	0	0.0
	1-2	0	0.0
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
<b>Out of work</b>	0	18	100.0
	1-2	0	0.0
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0

	0	4	80.0
	1-2	1	20.0
<b>Prefer not to say</b>	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
	0	317	96.06
	1-2	13	3.94
<b>Retired</b>	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
	0	15	88.24
	1-2	2	11.76
<b>Self-employed (full-time)</b>	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
	0	37	86.05
	1-2	5	11.63
<b>Self-employed (part-time)</b>	3-5	1	2.33
	5+	0	0.0
	No response	0	0.0
<b>Student</b>	0	15	75.0

	1-2	5	25.0
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
	0	259	87.21
<b>Unable to work</b>	1-2	28	9.43
	3-5	6	2.02
	5+	4	1.35
	No response	0	0.0
	0	21	91.3
<b>No response</b>	1-2	0	0.0
	3-5	1	4.35
	5+	1	4.35
	No response	0	0.0



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

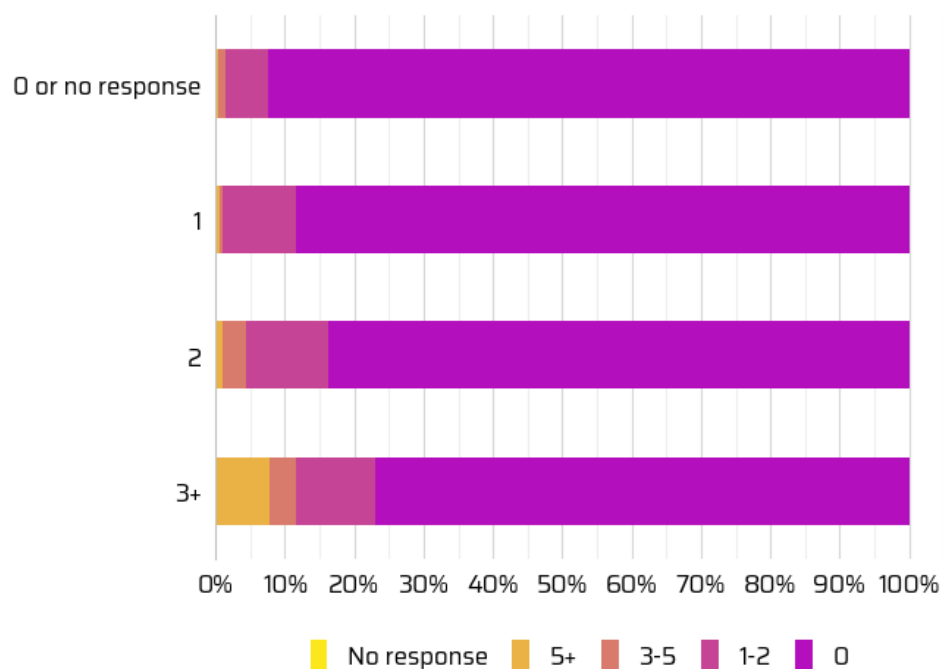


Figure 25 Frequency that NHS A&E/emergency services were sought, broken down by number of dependents

Table 25 Frequency that NHS A&E/emergency services were sought, broken down by number of dependents

Number of dependents	Frequency	Respondents	Percentage
<b>0 or no response</b>	0	653	92.36
	1-2	44	6.22
	3-5	7	0.99
	5+	3	0.42
	No response	0	0.0
<b>1</b>	0	168	88.42
	1-2	20	10.53
	3-5	1	0.53
	5+	1	0.53

	No response	0	0.0
	0	77	83.7
	1-2	11	11.96
<b>2</b>	3-5	3	3.26
	5+	1	1.09
	No response	0	0.0
	0	20	76.92
	1-2	3	11.54
<b>3+</b>	3-5	1	3.85
	5+	2	7.69
	No response	0	0.0

## Experience of healthcare overall

### Overall experience of healthcare

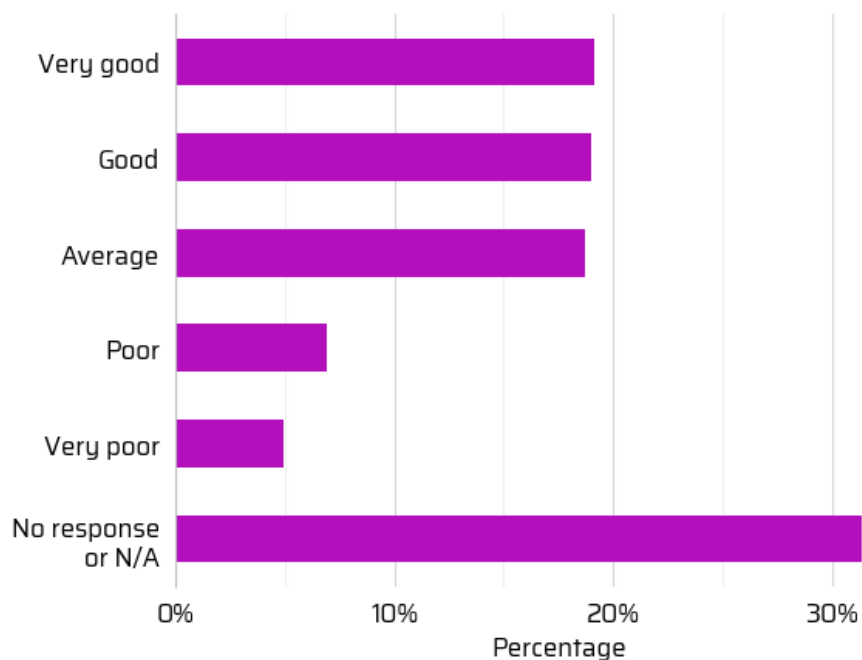


Figure 26 Overall experience of healthcare

Table 26 Overall experience of healthcare

Experience	Respondents	Percentage
Very good	194	19.11
Good	193	19.01
Average	190	18.72
Poor	70	6.9
Very poor	50	4.93
No response or N/A	318	31.33

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

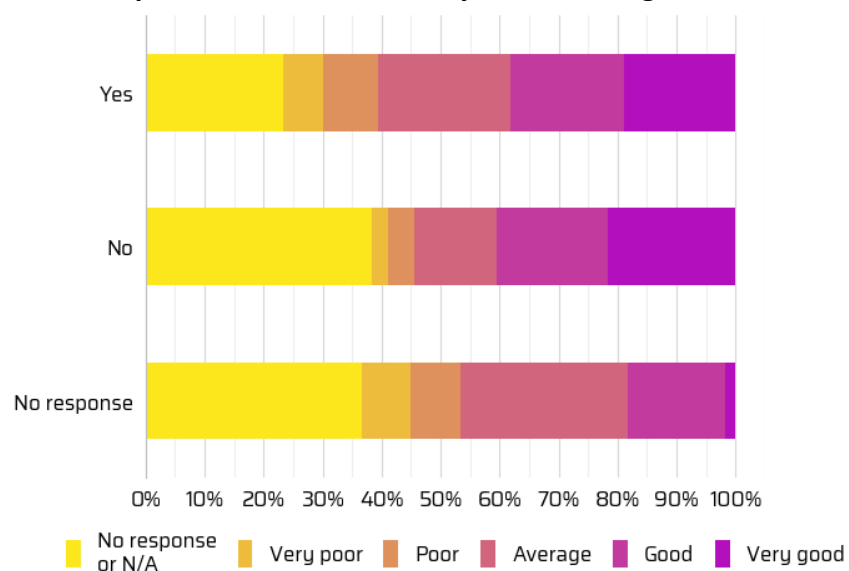


Figure 27 Overall experience of healthcare, broken down by whether diagnosed with multiple neurological conditions

Table 27 Overall experience of healthcare, broken down by whether diagnosed with multiple neurological conditions

Multiple neurological conditions	Experience	Respondents	Percentage
Yes	Very good	88	18.8
	Good	91	19.44
	Average	105	22.44
	Poor	43	9.19
	Very poor	32	6.84
	No response or N/A	109	23.29
No	Very good	105	21.56
	Good	92	18.89

	Average	68	13.96
	Poor	22	4.52
	Very poor	13	2.67
	No response or N/A	187	38.4
	Very good	1	1.67
	Good	10	16.67
	Average	17	28.33
<b>No response</b>	Poor	5	8.33
	Very poor	5	8.33
	No response or N/A	22	36.67

### Overall experience of healthcare by age group

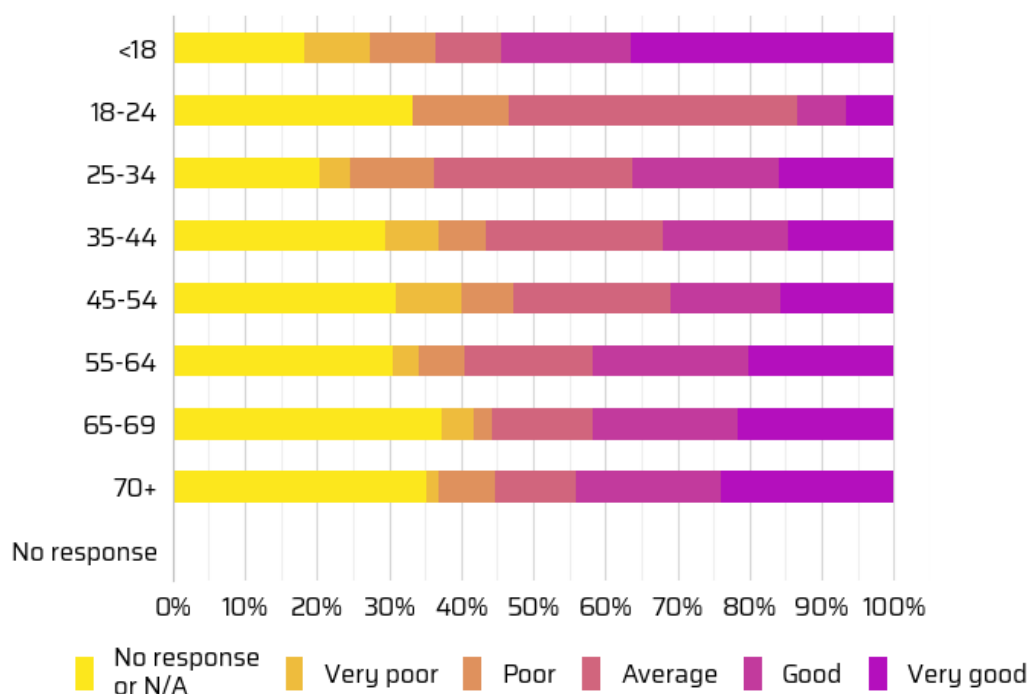


Figure 28 Overall experience of healthcare, broken down by age group

Table 28 Overall experience of healthcare, broken down by age group

Age	Experience	Respondents	Percentage
<b>&lt;18</b>	Very good	4	36.36
	Good	2	18.18
	Average	1	9.09
	Poor	1	9.09
	Very poor	1	9.09
	No response or N/A	2	18.18
<b>18-24</b>	Very good	1	6.67
	Good	1	6.67

	Average	6	40.0
	Poor	2	13.33
	Very poor	0	0.0
	No response or N/A	5	33.33
<b>25-34</b>	Very good	11	15.94
	Good	14	20.29
	Average	19	27.54
	Poor	8	11.59
	Very poor	3	4.35
	No response or N/A	14	20.29
<b>35-44</b>	Very good	18	14.75
	Good	21	17.21
	Average	30	24.59
	Poor	8	6.56
	Very poor	9	7.38
	No response or N/A	36	29.51
<b>45-54</b>	Very good	33	15.71
	Good	32	15.24
	Average	46	21.9

	Poor	15	7.14
	Very poor	19	9.05
	No response or N/A	65	30.95
	Very good	59	20.07
	Good	64	21.77
	Average	52	17.69
<b>55-64</b>	Poor	19	6.46
	Very poor	10	3.4
	No response or N/A	90	30.61
	Very good	25	21.74
	Good	23	20.0
	Average	16	13.91
<b>65-69</b>	Poor	3	2.61
	Very poor	5	4.35
	No response or N/A	43	37.39
	Very good	43	24.02
	Good	36	20.11
	Average	20	11.17
<b>70+</b>	Poor	14	7.82



	Very poor	3	1.68
	No response or N/A	63	35.2
	Very good	0	0.0
	Good	0	0.0
	Average	0	0.0
<b>No response</b>	Poor	0	0.0
	Very poor	0	0.0
	No response or N/A	0	0.0

### Overall experience of healthcare by gender

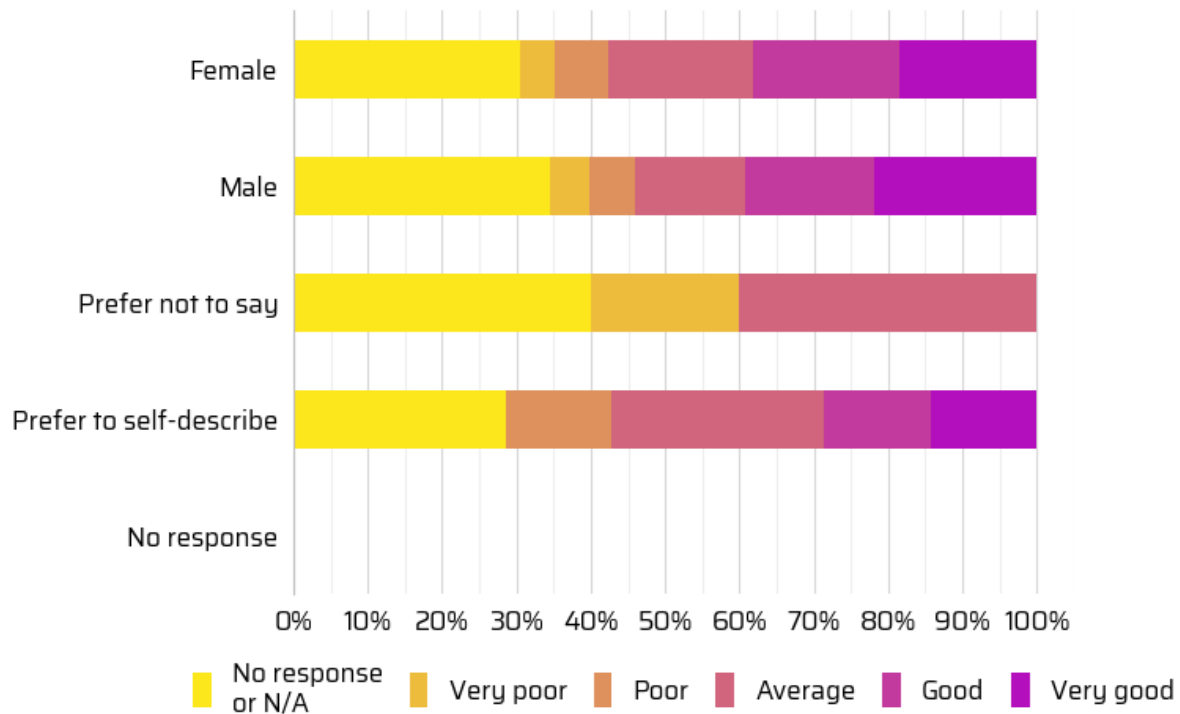


Figure 29 Overall experience of healthcare, broken down by gender

Table 29 Overall experience of healthcare, broken down by gender

Gender	Experience	Respondents	Percentage
<b>Female</b>	Very good	147	18.56
	Good	155	19.57
	Average	155	19.57
	Poor	56	7.07
	Very poor	38	4.8
	No response or N/A	241	30.43
<b>Male</b>	Very good	46	21.8
	Good	37	17.54
	Average	31	14.69
	Poor	13	6.16
	Very poor	11	5.21
	No response or N/A	73	34.6
<b>Prefer not to say</b>	Very good	0	0.0
	Good	0	0.0
	Average	2	40.0
	Poor	0	0.0
	Very poor	1	20.0
	No response or N/A	2	40.0

<b>Prefer to self-describe</b>	Very good	1	14.29
	Good	1	14.29
	Average	2	28.57
	Poor	1	14.29
	Very poor	0	0.0
	No response or N/A	2	28.57
<b>No response</b>	Very good	0	0.0
	Good	0	0.0
	Average	0	0.0
	Poor	0	0.0
	Very poor	0	0.0
	No response or N/A	0	0.0

### Overall experience of healthcare by employment status

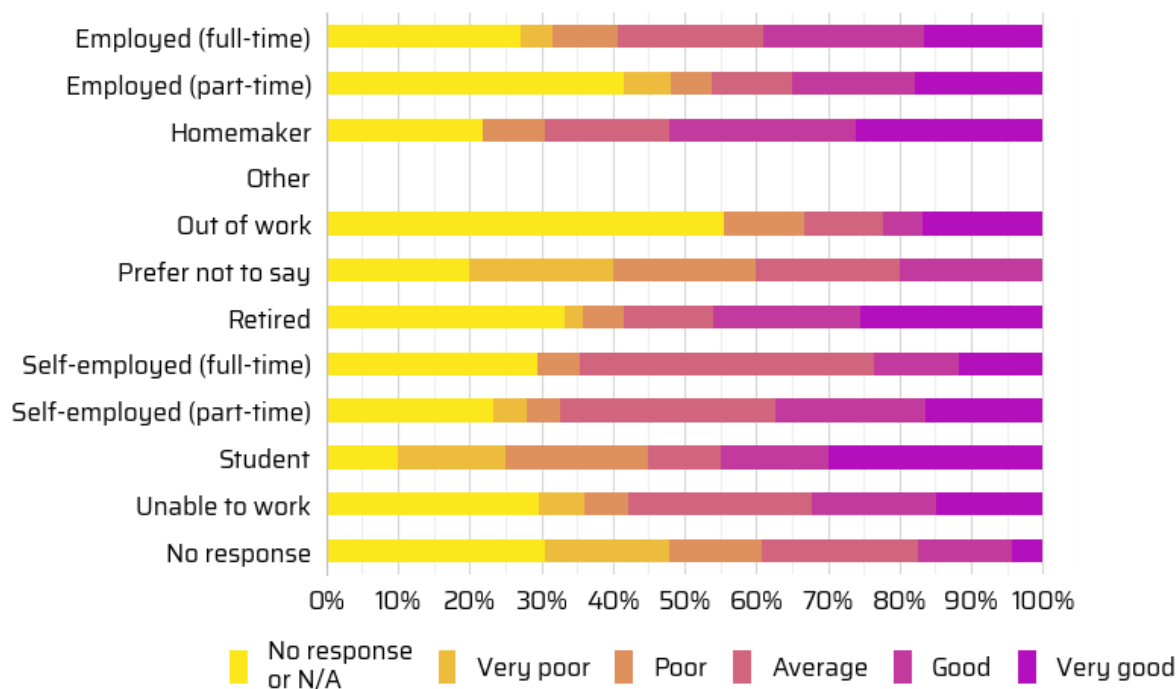


Figure 30 Overall experience of healthcare, broken down by employment status

Table 30 Overall experience of healthcare, broken down by employment status

Employment status	Experience	Respondents	Percentage
<b>Employed (full-time)</b>	Very good	22	16.54
	Good	30	22.56
	Average	27	20.3
	Poor	12	9.02
	Very poor	6	4.51
	No response or N/A	36	27.07
<b>Employed (part-time)</b>	Very good	19	17.92
	Good	18	16.98

	Average	12	11.32
	Poor	6	5.66
	Very poor	7	6.6
	No response or N/A	44	41.51
	Very good	6	26.09
	Good	6	26.09
	Average	4	17.39
<b>Homemaker</b>	Poor	2	8.7
	Very poor	0	0.0
	No response or N/A	5	21.74
	Very good	0	0.0
	Good	0	0.0
	Average	0	0.0
<b>Other</b>	Poor	0	0.0
	Very poor	0	0.0
	No response or N/A	0	0.0
	Very good	3	16.67
<b>Out of work</b>	Good	1	5.56
	Average	2	11.11

	Poor	2	11.11
	Very poor	0	0.0
	No response or N/A	10	55.56
	Very good	0	0.0
	Good	1	20.0
	Average	1	20.0
<b>Prefer not to say</b>	Poor	1	20.0
	Very poor	1	20.0
	No response or N/A	1	20.0
	Very good	84	25.45
	Good	68	20.61
	Average	41	12.42
<b>Retired</b>	Poor	19	5.76
	Very poor	8	2.42
	No response or N/A	110	33.33
	Very good	2	11.76
	Good	2	11.76
<b>Self-employed (full-time)</b>	Average	7	41.18
	Poor	1	5.88

	Very poor	0	0.0
	No response or N/A	5	29.41
	Very good	7	16.28
	Good	9	20.93
	Average	13	30.23
<b>Self-employed (part-time)</b>	Poor	2	4.65
	Very poor	2	4.65
	No response or N/A	10	23.26
	Very good	6	30.0
	Good	3	15.0
	Average	2	10.0
<b>Student</b>	Poor	4	20.0
	Very poor	3	15.0
	No response or N/A	2	10.0
	Very good	44	14.81
	Good	52	17.51
<b>Unable to work</b>	Average	76	25.59
	Poor	18	6.06
	Very poor	19	6.4

<b>No response</b>	No response or N/A	88	29.63
	Very good	1	4.35
	Good	3	13.04
	Average	5	21.74
	Poor	3	13.04
	Very poor	4	17.39
	No response or N/A	7	30.43

### Overall experience of healthcare by number of dependents

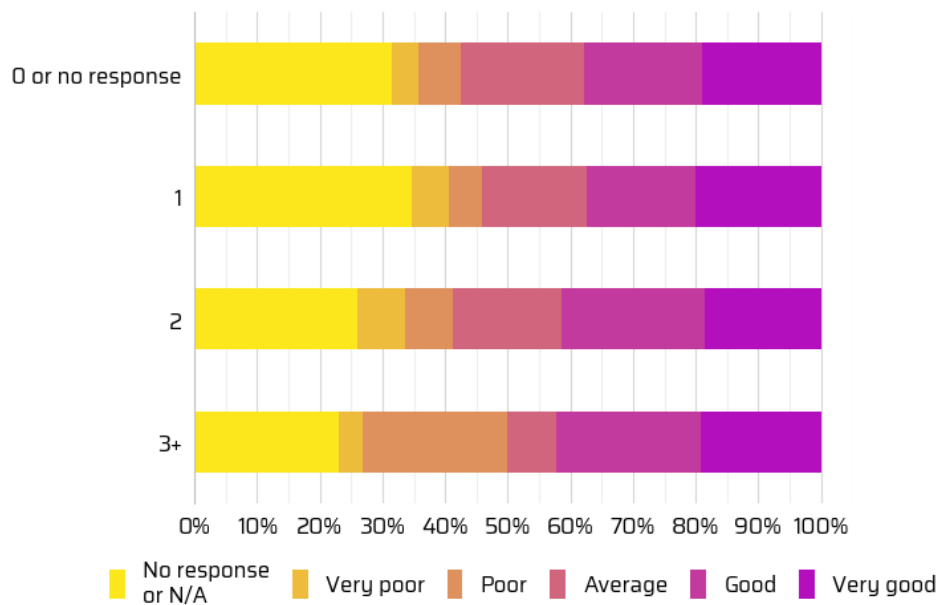


Figure 31 Overall experience of healthcare, broken down by number of dependents

Table 31 Overall experience of healthcare, broken down by number of dependents

Number of dependents	Experience	Respondents	Percentage
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	Very good	134	18.95
	Good	133	18.81
	Average	140	19.8
<b>0 or no response</b>	Poor	47	6.65
	Very poor	31	4.38
	No response or N/A	222	31.4
	Very good	38	20.0
	Good	33	17.37
	Average	32	16.84
<b>1</b>	Poor	10	5.26
	Very poor	11	5.79
	No response or N/A	66	34.74
	Very good	17	18.48
	Good	21	22.83
	Average	16	17.39
<b>2</b>	Poor	7	7.61
	Very poor	7	7.61
	No response or N/A	24	26.09
<b>3+</b>	Very good	5	19.23

Good	6	23.08
Average	2	7.69
Poor	6	23.08
Very poor	1	3.85
No response or N/A	6	23.08

## Demographics

### Sample size

Total number of respondents: 1015

### Gender

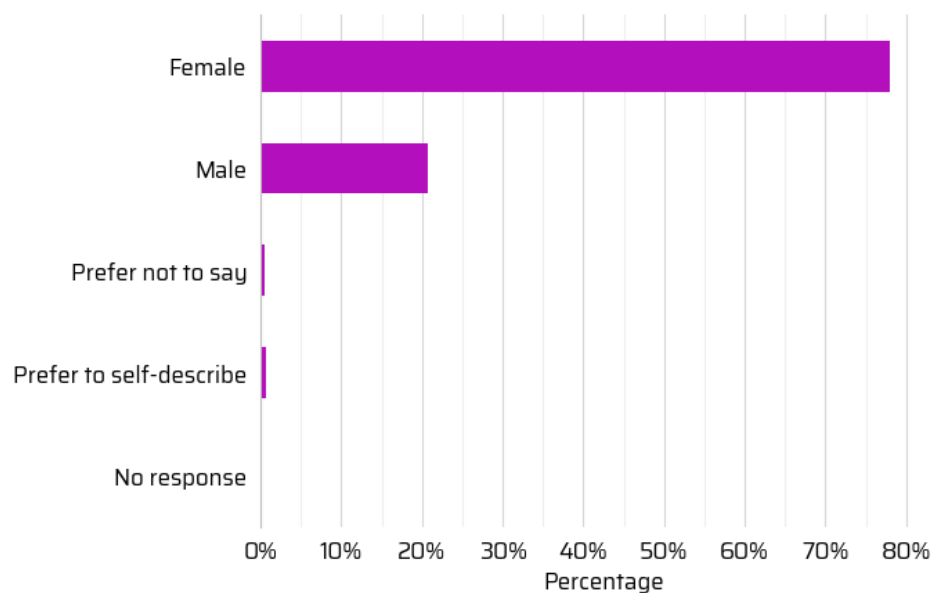


Figure 32 Gender of respondents

Table 32 Gender of respondents

Gender	Respondents	Percentage
Female	792	78.03

<b>Male</b>	211	20.79
<b>Prefer not to say</b>	5	0.49
<b>Prefer to self-describe</b>	7	0.69
<b>No response</b>	0	0.0

### Sexual orientation

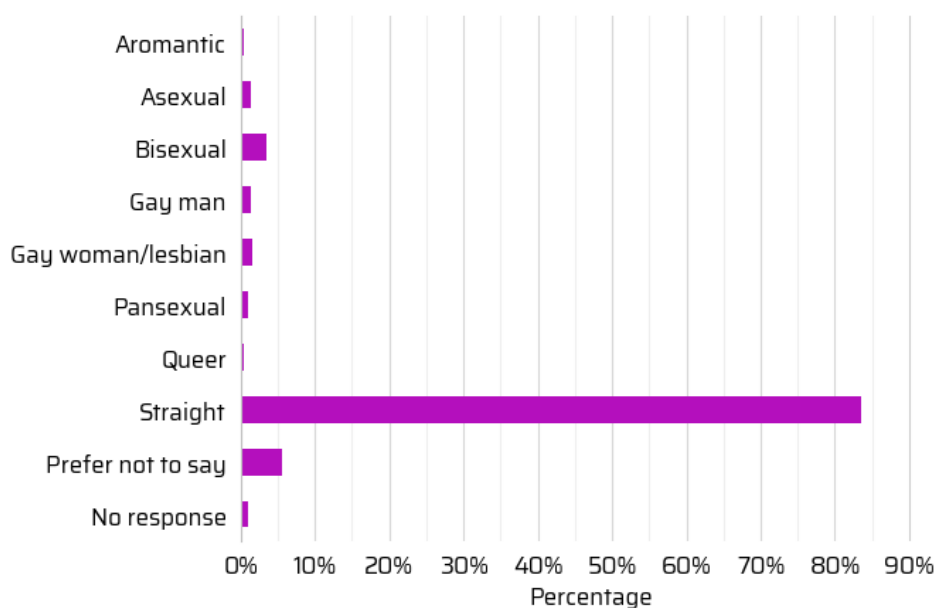


Figure 33 Sexual orientation of respondents

Table 33 Sexual orientation of respondents

<b>Sexual orientation</b>	<b>Respondents</b>	<b>Percentage</b>
<b>Aromantic</b>	4	0.39
<b>Asexual</b>	15	1.48
<b>Bisexual</b>	36	3.55
<b>Gay man</b>	14	1.38

<b>Gay woman/lesbian</b>	16	1.58
<b>Pansexual</b>	11	1.08
<b>Queer</b>	5	0.49
<b>Straight</b>	848	83.55
<b>Prefer not to say</b>	56	5.52
<b>No response</b>	10	0.99

### Age

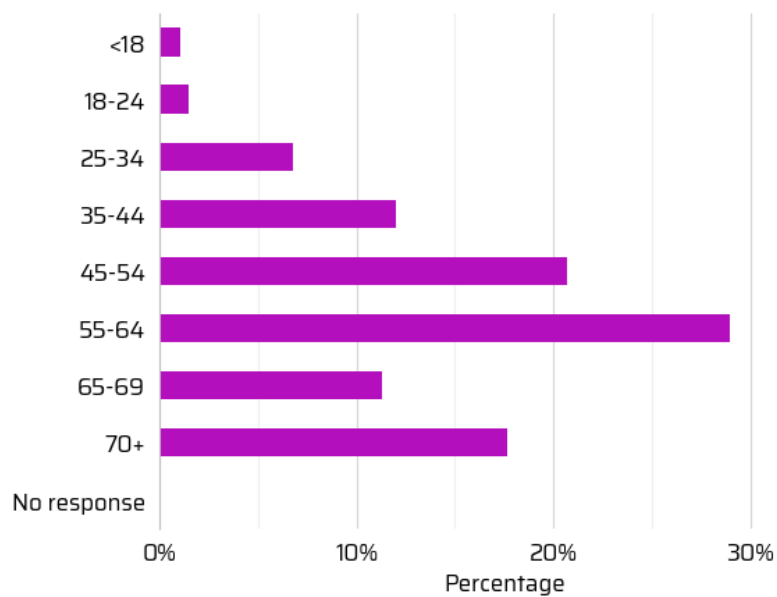


Figure 34 Age of respondents

Table 34 Age of respondents

<b>Age</b>	<b>Respondents</b>	<b>Percentage</b>
<b>&lt;18</b>	11	1.08
<b>18-24</b>	15	1.48
<b>25-34</b>	69	6.8

<b>35-44</b>	122	12.02
<b>45-54</b>	210	20.69
<b>55-64</b>	294	28.97
<b>65-69</b>	115	11.33
<b>70+</b>	179	17.64
<b>No response</b>	0	0.0

### Diagnosis status

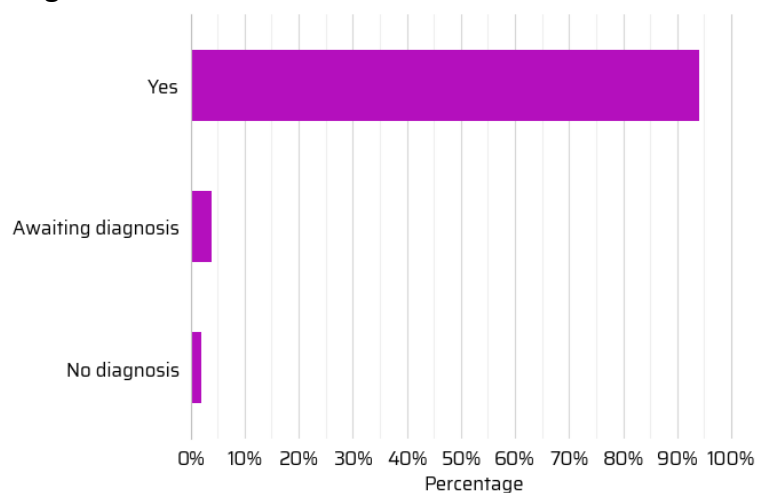


Figure 35 Diagnosis status of the respondents

Table 35 Diagnosis status of the respondents

<b>Diagnosis status</b>	<b>Respondents</b>	<b>Percentage</b>
<b>Yes</b>	955	94.09
<b>Awaiting diagnosis</b>	40	3.94
<b>No diagnosis</b>	20	1.97

### Diagnosis recency

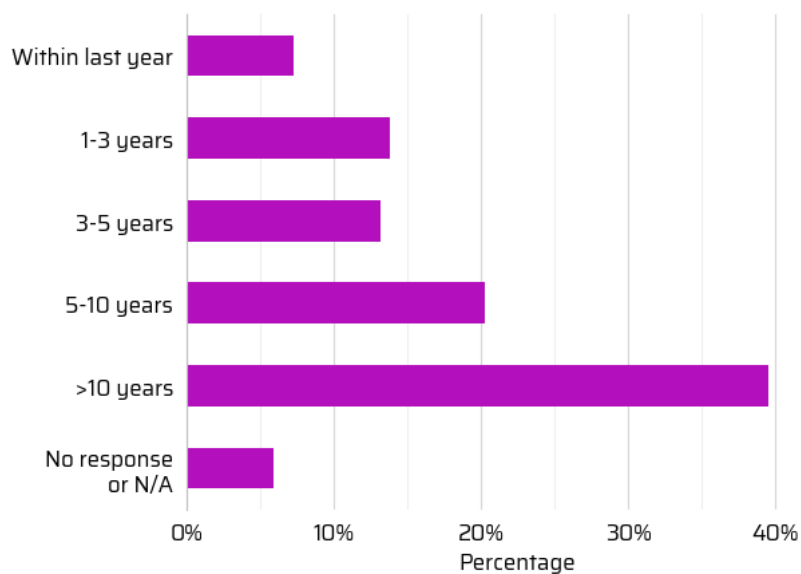


Figure 36 Recency of the respondents' first neurological condition diagnosis

Table 36 Recency of the respondents' first neurological condition diagnosis

Recency	Respondents	Percentage
Within last year	74	7.29
1-3 years	140	13.79
3-5 years	134	13.2
5-10 years	206	20.3
>10 years	401	39.51
No response or N/A	60	5.91

## Location



*Figure 37 Location of the respondents*

*Table 37 Location of the respondents*

<b>Regions</b>	<b>Respondents</b>	<b>Percentage</b>
<b>Midlands</b>	150	14.78
<b>South East</b>	132	13.0
<b>South West</b>	113	11.13
<b>East of England</b>	108	10.64
<b>North East and Yorkshire</b>	101	9.95
<b>London</b>	89	8.77
<b>Scotland</b>	69	6.8
<b>North West</b>	60	5.91
<b>Wales</b>	53	5.22
<b>Northern Ireland</b>	21	2.07
<b>Isle of Man</b>	2	0.2
<b>No/invalid response</b>	182	17.93

Note: The regions in England are further divided into 'NHS England Regions'. We asked respondents for the first part of their postcodes. 62 of the respondents have postcodes that span across two or more regions on the map. e.g. some postcodes span across both London and South East, or both Wales and Midlands, etc. Therefore, we do not have the information about which of the two regions these respondents are actually in. For Figure 5 and Table 5, if a postcode spans across two areas, we add 1 to each of these areas. 182 respondents did not provide their postcodes or offered invalid postcodes, and therefore were not included in this analysis.



## Employment status

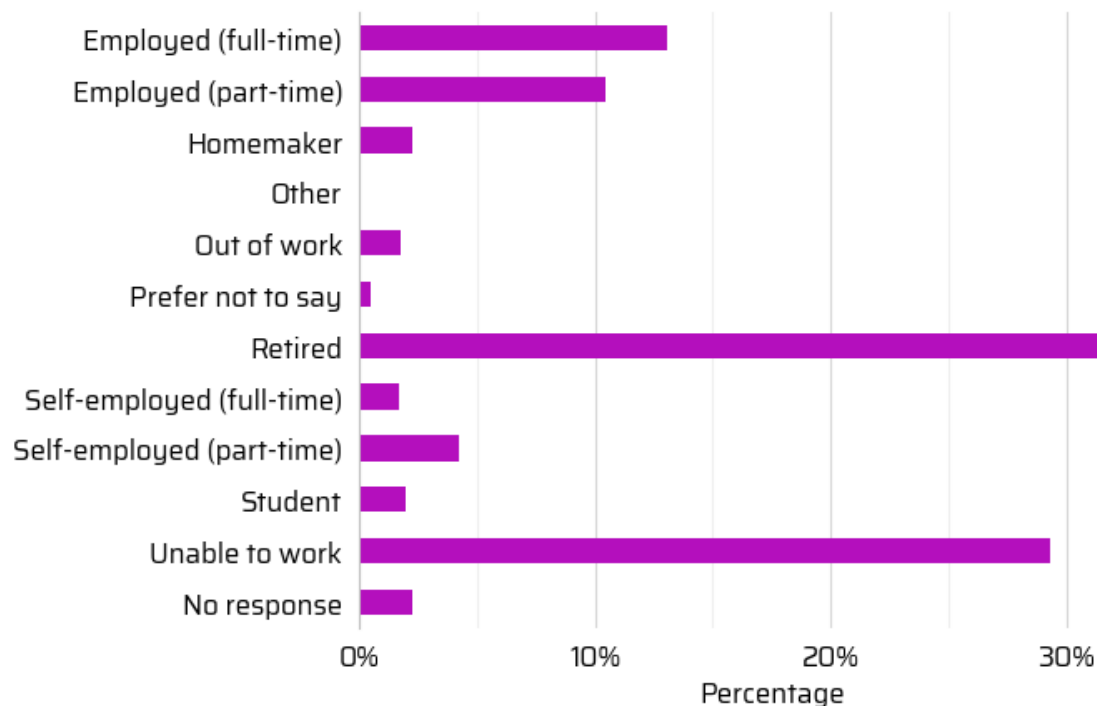


Figure 38 Employment status of respondents

Table 38 Employment status of respondents

Employment status	Respondents	Percentage
Employed (full-time)	133	13.1
Employed (part-time)	106	10.44
Homemaker	23	2.27
Other	0	0.0
Out of work	18	1.77
Prefer not to say	5	0.49
Retired	330	32.51
Self-employed (full-time)	17	1.67
Self-employed (part-time)	43	4.24

<b>Student</b>	20	1.97
<b>Unable to work</b>	297	29.26
<b>No response</b>	23	2.27

### Neurological conditions

Note: A single respondent may have multiple neurological conditions, so the total number of conditions may not add up to the total number of respondents. The percentages provided indicate the proportion of responses relative to the total number of respondents. 468 respondents (46.11% of the respondents that had answered this question) indicated that they have multiple neurological conditions.

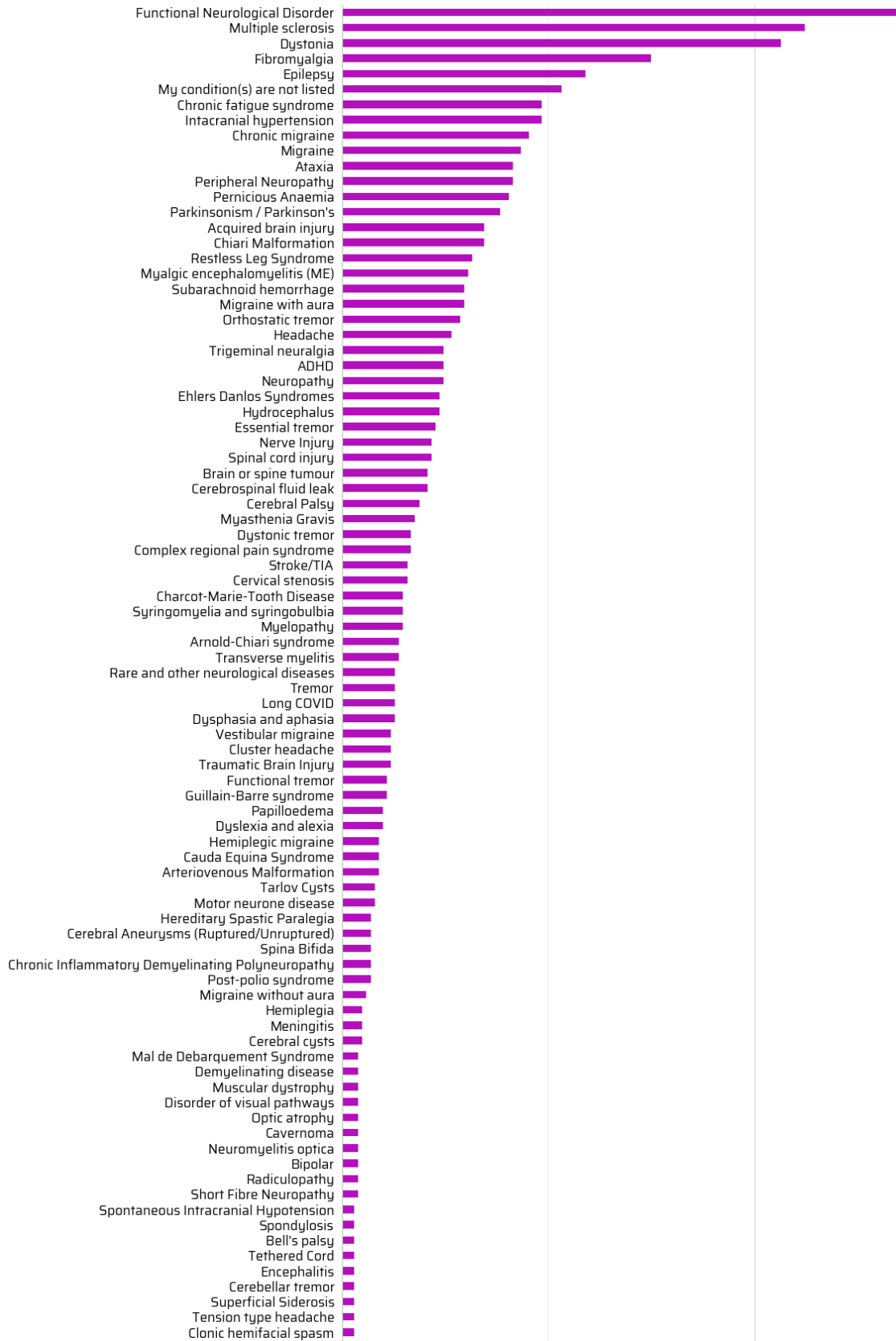




Figure 39 Neurological conditions respondents had been diagnosed with

Table 39 Neurological conditions respondents had been diagnosed with

Condition	Respondents	Percentage
<b>Functional Neurological Disorder</b>	137	13.5
<b>Multiple sclerosis</b>	114	11.23
<b>Dystonia</b>	108	10.64
<b>Fibromyalgia</b>	76	7.49
<b>Epilepsy</b>	60	5.91
<b>My condition(s) are not listed</b>	54	5.32
<b>Chronic fatigue syndrome</b>	49	4.83
<b>Intacranial hypertension</b>	49	4.83
<b>Chronic migraine</b>	46	4.53

<b>Migraine</b>	44	4.33
<b>Ataxia</b>	42	4.14
<b>Peripheral Neuropathy</b>	42	4.14
<b>Pernicious Anaemia</b>	41	4.04
<b>Parkinsonism / Parkinson's</b>	39	3.84
<b>Acquired brain injury</b>	35	3.45
<b>Chiari Malformation</b>	35	3.45
<b>Restless Leg Syndrome</b>	32	3.15
<b>Myalgic encephalomyelitis (ME)</b>	31	3.05
<b>Subarachnoid hemorrhage</b>	30	2.96
<b>Migraine with aura</b>	30	2.96
<b>Orthostatic tremor</b>	29	2.86
<b>Headache</b>	27	2.66
<b>Trigeminal neuralgia</b>	25	2.46
<b>ADHD</b>	25	2.46
<b>Neuropathy</b>	25	2.46
<b>Ehlers Danlos Syndromes</b>	24	2.36
<b>Hydrocephalus</b>	24	2.36
<b>Essential tremor</b>	23	2.27
<b>Spinal cord injury</b>	22	2.17

<b>Nerve Injury</b>	22	2.17
<b>Cerebrospinal fluid leak</b>	21	2.07
<b>Brain or spine tumour</b>	21	2.07
<b>Cerebral Palsy</b>	19	1.87
<b>Myasthenia Gravis</b>	18	1.77
<b>Dystonic tremor</b>	17	1.67
<b>Complex regional pain syndrome</b>	17	1.67
<b>Stroke/TIA</b>	16	1.58
<b>Cervical stenosis</b>	16	1.58
<b>Charcot-Marie-Tooth Disease</b>	15	1.48
<b>Syringomyelia and syringobulbia</b>	15	1.48
<b>Myelopathy</b>	15	1.48
<b>Transverse myelitis</b>	14	1.38
<b>Arnold-Chiari syndrome</b>	14	1.38
<b>Long COVID</b>	13	1.28
<b>Dysphasia and aphasia</b>	13	1.28
<b>Rare and other neurological diseases</b>	13	1.28
<b>Tremor</b>	13	1.28
<b>Vestibular migraine</b>	12	1.18

<b>Cluster headache</b>	12	1.18
<b>Traumatic Brain Injury</b>	12	1.18
<b>Functional tremor</b>	11	1.08
<b>Guillain-Barre syndrome</b>	11	1.08
<b>Papilloedema</b>	10	0.99
<b>Dyslexia and alexia</b>	10	0.99
<b>Cauda Equina Syndrome</b>	9	0.89
<b>Arteriovenous Malformation</b>	9	0.89
<b>Hemiplegic migraine</b>	9	0.89
<b>Motor neurone disease</b>	8	0.79
<b>Tarlov Cysts</b>	8	0.79
<b>Hereditary Spastic Paralegia</b>	7	0.69
<b>Post-polio syndrome</b>	7	0.69
<b>Cerebral Aneurysms (Ruptured/Unruptured)</b>	7	0.69
<b>Spina Bifida</b>	7	0.69
<b>Chronic Inflammatory Demyelinating Polyneuropathy</b>	7	0.69
<b>Migraine without aura</b>	6	0.59
<b>Hemiplegia</b>	5	0.49

<b>Meningitis</b>	5	0.49
<b>Cerebral cysts</b>	5	0.49
<b>Short Fibre Neuropathy</b>	4	0.39
<b>Radiculopathy</b>	4	0.39
<b>Cavernoma</b>	4	0.39
<b>Bipolar</b>	4	0.39
<b>Neuromyelitis optica</b>	4	0.39
<b>Demyelinating disease</b>	4	0.39
<b>Optic atrophy</b>	4	0.39
<b>Disorder of visual pathways</b>	4	0.39
<b>Mal de Debarquement Syndrome</b>	4	0.39
<b>Muscular dystrophy</b>	4	0.39
<b>Clonic hemifacial spasm</b>	3	0.3
<b>Tension type headache</b>	3	0.3
<b>Superficial Siderosis</b>	3	0.3
<b>Cerebellar tremor</b>	3	0.3
<b>Spontaneous Intracranial Hypotension</b>	3	0.3
<b>Tethered Cord</b>	3	0.3
<b>Encephalitis</b>	3	0.3



<b>Bell's palsy</b>	3	0.3
<b>Spondylosis</b>	3	0.3
<b>Disorders of multiple cranial nerves</b>	2	0.2
<b>Disorders of vagus nerve</b>	2	0.2
<b>Apraxia</b>	2	0.2
<b>Neurofibromatosis</b>	2	0.2
<b>Dementia</b>	2	0.2
<b>Hemicrania continua</b>	2	0.2
<b>Acute poliomyelitis</b>	2	0.2
<b>Cranial nerve disorder</b>	2	0.2
<b>Disorders of other specified cranial nerves</b>	2	0.2
<b>Paraplegia and tetraplegia</b>	2	0.2
<b>Tourette Syndrome</b>	2	0.2
<b>Myositis</b>	2	0.2
<b>Menstrual migraine</b>	2	0.2
<b>Spinal CSF Leak</b>	2	0.2
<b>Disorders of other visual pathways</b>	2	0.2
<b>Narcolepsy and cataplexy</b>	1	0.1
<b>Facial myokymia</b>	1	0.1

<b>Schwanomatosis</b>	1	0.1
<b>Nerve Tumour</b>	1	0.1
<b>Faetal Alcohol Spectrum Disorders (FASD)</b>	1	0.1
<b>Dysexecutive Syndrome</b>	1	0.1
<b>Cyclical vomiting syndrome</b>	1	0.1
<b>Amoebic brain abscess</b>	1	0.1
<b>Malaria</b>	1	0.1
<b>Migraine with brainstem aura</b>	1	0.1
<b>Agnosia</b>	1	0.1
<b>Abdominal migraine</b>	1	0.1
<b>Brown-Séquard syndrome</b>	1	0.1
<b>Intracranial abscess and granuloma</b>	1	0.1
<b>Dysarthria and anarthria</b>	1	0.1
<b>Multiple system atrophy</b>	1	0.1
<b>Parkinsonian tremor</b>	1	0.1
<b>Myopathy</b>	1	0.1

### Additional neurological conditions/symptoms

Respondents were asked to list any neurological conditions/symptoms that they experience that are not listed in the prior questions. Some of the most frequently mentioned ones are as below:

Table 40 Additional neurological conditions/symptoms

Conditions/Symptoms	Respondents	Other phrasings described by the respondents
<b>Anxiety</b>	11	
<b>Fatigue</b>	10	Neuro fatigue, chronic fatigue
<b>Neuralgia</b>	9	Occipital neuralgia, cervical neuralgia, trigeminal neuralgia, Post herpetic neuralgia, Glossopharyngeal neuralgia
<b>Vision problems</b>	9	Blurred vision, sight loss, blurry eyesight
<b>Depression</b>	8	
<b>Tinnitus</b>	8	
<b>Pins/ needles/numbness/tingling</b>	8	
<b>Neck pain/stiffness</b>	7	
<b>Balance problems</b>	7	
<b>Memory loss/problems</b>	7	
<b>Non-Epileptic Attack Disorder/ Non epileptic seizures / Functional seizures</b>	7	
<b>Brain fog</b>	6	
<b>Adhesive Arachnoiditis</b>	6	

<b>Tremor</b>	6	
<b>Sleep problems</b>	6	Sleep apnoea, sleep paralysis, sleep difficulties, poor sleep
<b>Sciatica</b>	6	
<b>Cognitive problems</b>	6	Cognitive fatigue, functional cognitive disorder, Cerebellar Cognitive Affective Syndrome
<b>Neuropathy</b>	5	Peripheral neuropathy, sensory neuropathy, small fibre neuropathy, sensorimotor axonal neuropathy
<b>Aphasia</b>	5	Nominal Aphasia, transient aphasia, Nomic aphasia
<b>Back pain</b>	4	
<b>Pituitary Tumour</b>	4	Pituitary macroadenoma
<b>Should pain/stiffness</b>	4	
<b>Mobility problems</b>	4	
<b>Disc problems</b>	4	
<b>Hearing loss</b>	4	
<b>Spasms</b>	4	
<b>Bowel and/or bladder issues</b>	4	
<b>Compression of nerves</b>	3	
<b>Spinal Stenosis</b>	3	
<b>Progressive supranuclear palsy</b>	3	

<b>Speech problems</b>	3	
<b>Dysphonia</b>	3	Spasmodic abductor dysphonia, Blepharospasm Dysphonia
<b>Holnes Adies syndrome</b>	3	
<b>Radiculopathy</b>	3	
<b>Burning sensation</b>	3	
<b>Dizziness</b>	3	

### Symptoms without diagnosis

Table 41 Some of the most common symptoms experienced by respondents awaiting diagnosis.

<b>Conditions/Symptoms</b>	<b>Respondents</b>	<b>Other phrasings described by the respondents</b>
<b>Pins/ needles/numbness/tingling</b>	17	
<b>Fatigue</b>	16	Neuro fatigue
<b>Headache</b>	8	Orthostatic headache
<b>Brain fog</b>	7	
<b>Gait/mobility problems</b>	6	
<b>Neuropathy</b>	5	Peripheral neuropathy, neuropathy of fingers and toes
<b>Tinnitus</b>	5	
<b>Burning sensation</b>	5	
<b>Memory problems/loss</b>	5	

<b>Dizziness</b>	5
<b>Bladder problems</b>	4
<b>Depression</b>	4
<b>Neck pain</b>	3
<b>Loss of sensation</b>	3
<b>Cold feelings in limbs</b>	3
<b>Stroke-like symptoms/episodes</b>	3
<b>Balance problems</b>	3
<b>Speech problems</b>	3
<b>Nausea</b>	3
<b>Tics</b>	3
<b>Ataxia</b>	3

### Multiple neurological conditions

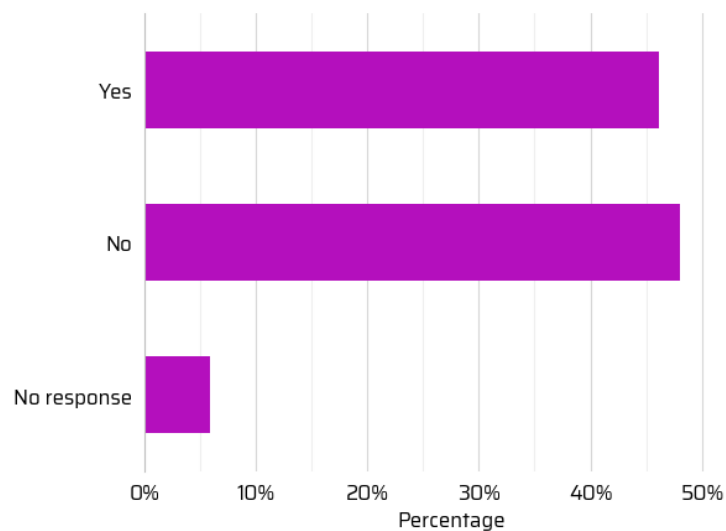


Figure 40 Whether respondents were diagnosed with multiple neurological conditions

Table 42 Whether respondents were diagnosed with multiple neurological conditions

Multiple neurological conditions	Respondents	Percentage
Yes	468	46.11
No	487	47.98
No response	60	5.91

### Number of non-neurological co-occurring conditions

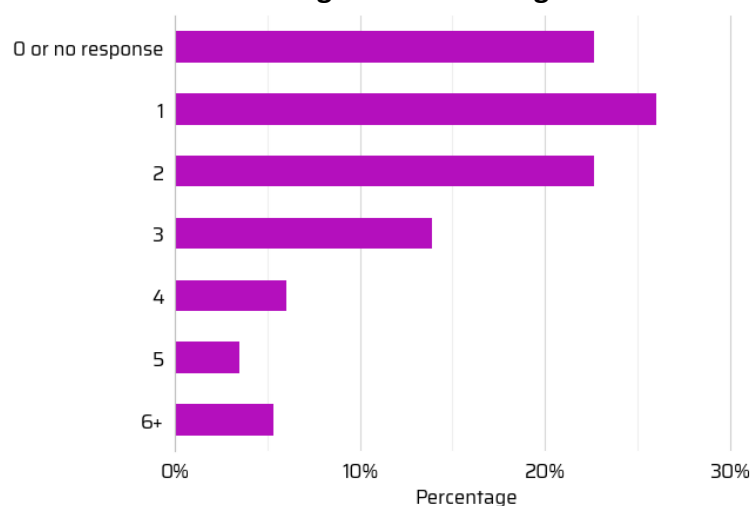


Figure 41 Number of non-neurological conditions that respondents were diagnosed with that co-occur with their neurological condition(s)

Table 43 Number of non-neurological conditions that respondents were diagnosed with that co-occur with their neurological condition(s)

Number of conditions	Respondents	Percentage
0 or no response	230	22.66
1	264	26.01
2	230	22.66

<b>3</b>	<b>141</b>	<b>13.89</b>
<b>4</b>	<b>61</b>	<b>6.01</b>
<b>5</b>	<b>35</b>	<b>3.45</b>
<b>6+</b>	<b>54</b>	<b>5.32</b>

**Ethnic group**

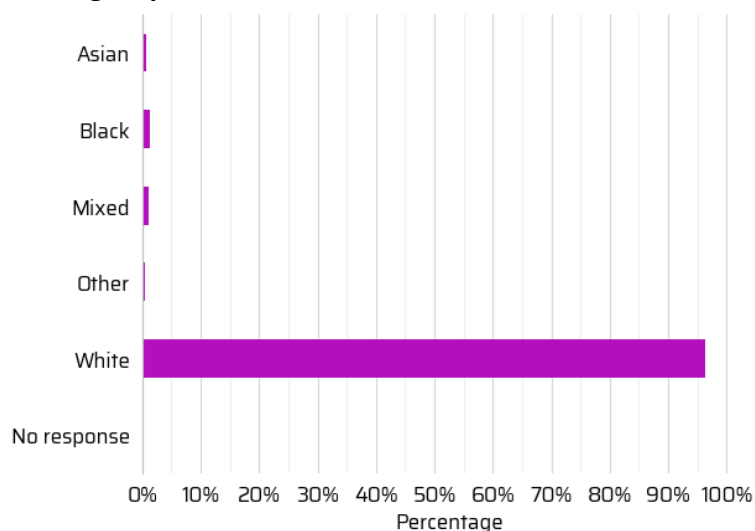


Figure 42 Ethnic group of respondents

Table 44 Ethnic group of respondents

<b>Ethnic group</b>	<b>Respondents</b>	<b>Percentage</b>
<b>Asian</b>	<b>7</b>	<b>0.69</b>
<b>Black</b>	<b>14</b>	<b>1.38</b>
<b>Mixed</b>	<b>11</b>	<b>1.08</b>
<b>Other</b>	<b>4</b>	<b>0.39</b>
<b>White</b>	<b>979</b>	<b>96.45</b>



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<b>No response</b>	<b>0</b>	<b>0.0</b>
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**Number of dependents**

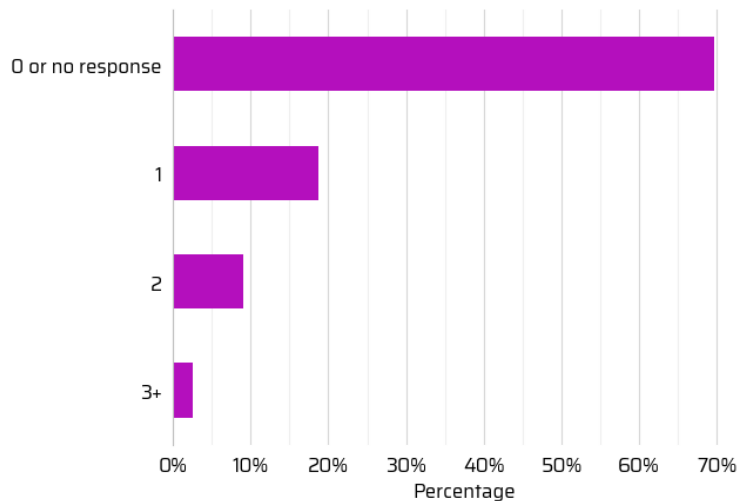


Figure 43 Number of dependents of respondents

Table 45 Number of dependents of respondents

<b>Number of dependents</b>	<b>Respondents</b>	<b>Percentage</b>
<b>0 or no response</b>	707	69.66
<b>1</b>	190	18.72
<b>2</b>	92	9.06
<b>3+</b>	26	2.56

## Receiving care or support

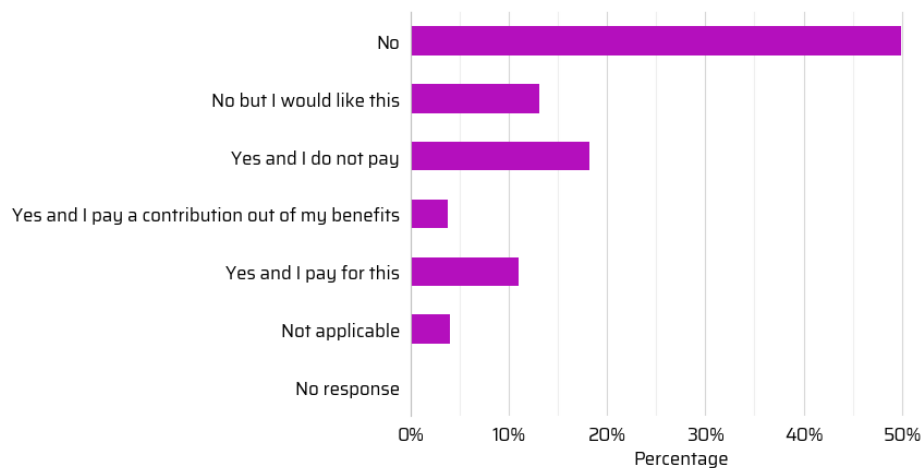


Figure 44 Whether respondents receiving care or support

Table 46 Whether respondents receiving care or support

Receive care/support	Respondents	Percentage
<b>No</b>	507	49.95
<b>No but I would like this</b>	133	13.1
<b>Yes and I do not pay</b>	185	18.23
<b>Yes and I pay a contribution out of my benefits</b>	38	3.74
<b>Yes and I pay for this</b>	111	10.94
<b>Not applicable</b>	41	4.04
<b>No response</b>	0	0.0