## NeuroLifeNow
### It's time to make your story heard

**January – February 2024 - Full Insights Report**

**Priorities for the new UK Government to focus on for people living with neurological condition(s)**

Brain & Spine Foundation    THE NEUROLOGICAL ALLIANCE    COMMUNITY FUND

## About NeuroLifeNow

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

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

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

# Foreword

As the dust settles following the UK General Election, and the new Labour Government establishes their priorities, this report is a timely reminder of what the new UK Government needs to get to work on without delay, for people affected by neurological conditions.

In January and February, you were clear about your priorities for the new Government – improve access to specialists, and quickly.  9 out of 10 people who responded to NeuroLifeNow said this was a priority for them.

**New Neuro Champions elected**

At the Neurological Alliance, we are carefully thinking about how we can work together to ensure Labour prioritises the needs of people affected by neurological conditions. More than 1000 people wrote to their local candidates during the General Election to call on them to become a 'Neuro Champion' if elected – that means speaking up and out on the issues that matter to people living with neurological conditions, including improving access to specialists. 11 MPs have already signed up to become a Neuro Champion as a result, and many more are being approached about signing up now they have been elected.

In the January-February survey, many people indicated that they would be willing to play a more active campaigning role with the new Government – 27% said they would speak to the local press about their experiences, and 16% said they would speak up with their local politicians at an event. We will use these helpful insights to shape the next phase of the Neuro Champion campaign, ensuring we provide a number of ways for people to speak up and out about their experiences.

**Access to support remains patchy, but important**

71% of people said they found their medical appointments helpful, and 74% of people who had an appointment had face to face appointments. This is a

distinct shift from the heights of the pandemic, where telephone and videoconference appointments were used more routinely. It is critical that people affected by neurological conditions are given a choice for appointment format – possibly avoiding lengthy travel, but also ensuring people are able to access face to face time with healthcare professionals when they need it.

**Mental health needs are not being met**

Worryingly, the percentage of people reporting that their mental health needs are not being met at all is high – nearly 4 in 10 reported this in January and February. The NHS in England has confirmed that no person with a neurological condition should be turned away for mental health support if they need it. We are working hard to ensure this is implemented, and that countries across the UK make a similar promise. Importantly, we want to see commitments from Governments across the UK to grow the health and care workforce for mental health too.

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.

Thank you,

**The Brain & Spine Foundation Team**

**Georgina Carr, CEO, The Neurological Alliance, England**

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## Key Findings

We received **650 responses** in January to February 2024. **109 conditions** were represented, and 46% of people reported living with more than one condition. We asked respondents to list any neurological conditions/symptoms that they experience that are not listed in the prior questions. **Anxiety** and **memory problems** were listed most often.

**45% of respondents were diagnosed 10 or more years ago**. 76% said their neurological condition(s) **impacted their life to a great or large extent**.

**90%** of people said **improving access to specialists** was a **priority** for the **next UK Government**. 52% said access to appropriate **mental health support** should be a priority, and 51% said access to **financial support**.

**50% of respondents said they would use email candidates to campaign for change**, 47% said they would use **key messaging** and 44% said they would use **social media templates**.

**16% of people said they were confident enough** to **write** to their **local candidates** by post, 43% said they were confident to write to them using email. 7% said they were confident enough to **take part in a stunt or protest to campaign**, 16% said this about speaking to the local press.

**64% of respondents said they had at least one medical appointment in the eight weeks before taking the survey.** 25% said they had three or more appointments.

**72% of those who had appointments said they found them helpful.** 38% had an appointment with their GP, 17% with their specialist nurse and 14% with a neurologist.

**74%** reported having a **face-to-face appointment**.

**57% said they felt anxious, 31% said they felt hopeless.** Just 17% felt well supported. In parallel, 39% of people said their mental health needs were not being met at all. Those with multiple neurological conditions were more likely to report this (46%).

# UK General Election priorities and campaign

## Priorities for the next UK Government
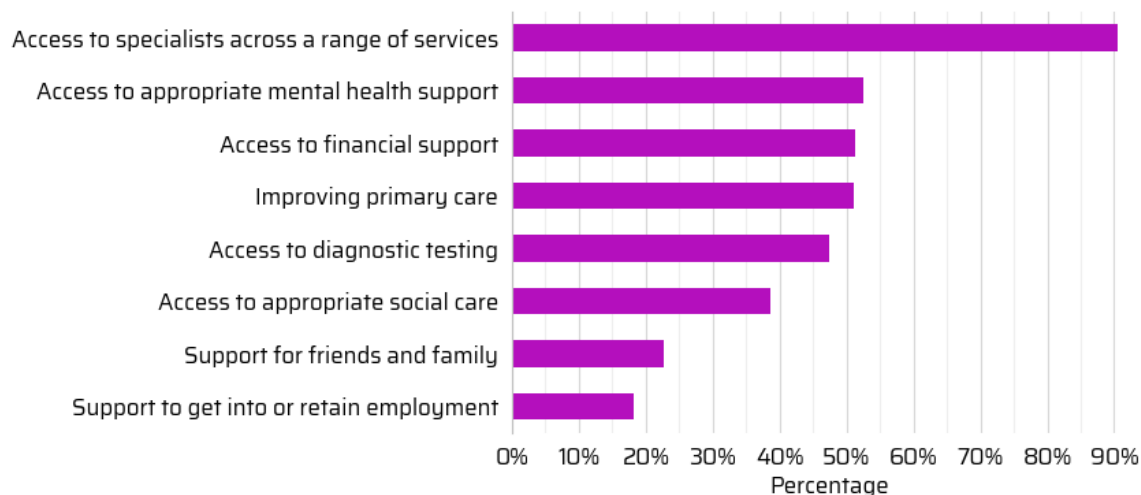


Figure 1: Priorities for the next UK Government.

Table 1: Priorities for the next UK Government.

| Response | Respondents | Percentage |
| --- | --- | --- |
| **Access to specialists across a range of services** | 588 | 90.46 |
| **Access to appropriate mental health support** | 341 | 52.46 |
| **Access to financial support** | 333 | 51.23 |
| **Improving primary care** | 332 | 51.08 |
| **Access to diagnostic testing** | 308 | 47.38 |
| **Access to appropriate social care** | 251 | 38.62 |
| **Support for friends and family** | 147 | 22.62 |

| | | |
|---|---|---|
| **Support to get into or retain employment** | 118 | 18.15 |

Note: Each respondent can select multiple responses for this question, so the total number of responses may not match the total number of respondents. The percentages provided indicate the proportion of responses relative to the total number of respondents.

## Support from charities to campaign
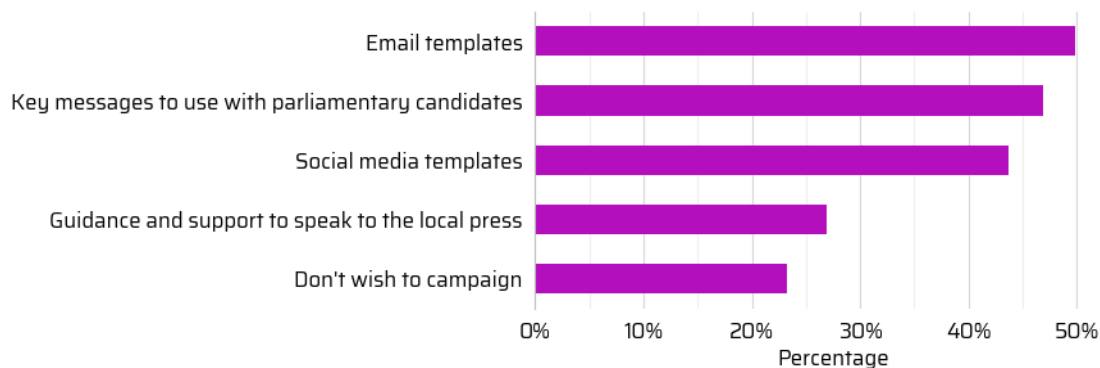
Figure 2: Support from charities to campaign.

Table 2: Support from charities to campaign.

| Response | Respondents | Percentage |
|---|---|---|
| **Email templates** | 324 | 49.85 |
| **Key messages to use with parliamentary candidates** | 305 | 46.92 |
| **Social media templates** | 284 | 43.69 |
| **Guidance and support to speak to the local press** | 175 | 26.92 |
| **Don't wish to campaign** | 151 | 23.23 |

Note: Each respondent can select multiple responses for this question, so the total number of responses may not match the total number of respondents. The percentages provided indicate the proportion of responses relative to the total number of respondents.

## Level of confidence for campaign actions

### Asking Parliamentary candidates, a question at a local event.
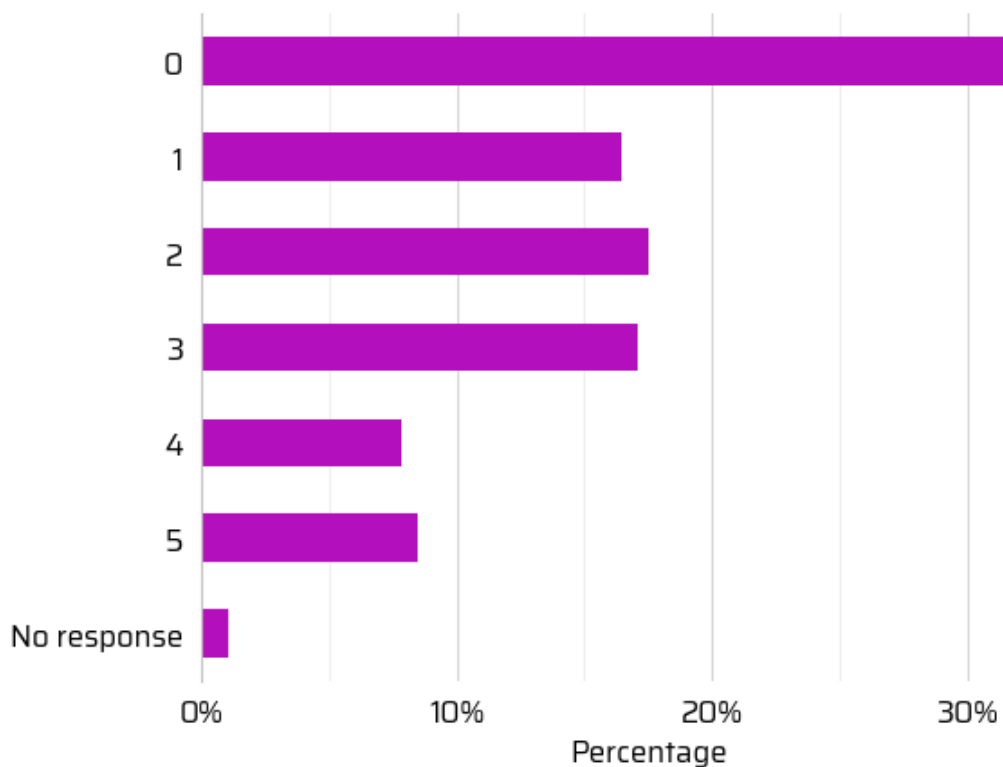


Figure 3 Level of confidence for asking Parliamentary candidates a question at a local event.

Table 3 Level of confidence for asking Parliamentary candidates a question at a local event.

| Level of confidence | Respondents | Percentage |
|---|---|---|
| 0 | 205 | 31.54 |
| 1 | 107 | 16.46 |
| 2 | 114 | 17.54 |
| 3 | 111 | 17.08 |
| 4 | 51 | 7.85 |
| 5 | 55 | 8.46 |
| No response | 7 | 1.08 |

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## Writing to your local candidates by post.
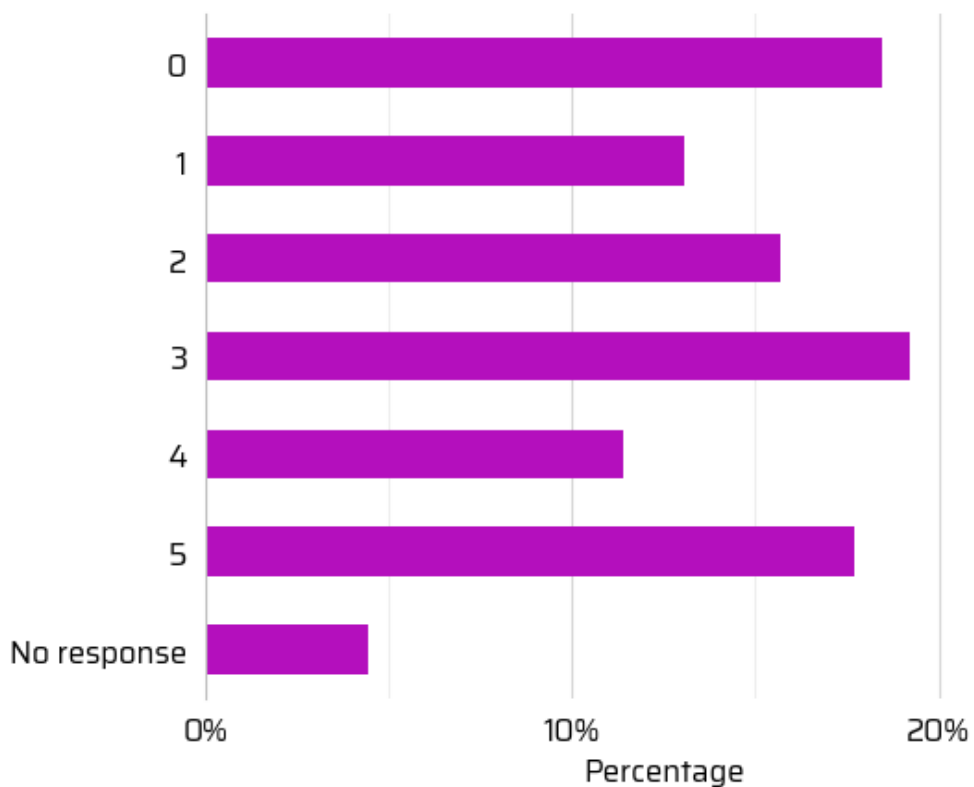


Figure 4: Level of confidence for writing to your local candidates by post.

Table 4: Level of confidence for writing to your local candidates by post.

| Level of confidence | Respondents | Percentage |
|---|---|---|
| **0** | 120 | 18.46 |
| **1** | 85 | 13.08 |
| **2** | 102 | 15.69 |
| **3** | 125 | 19.23 |
| **4** | 74 | 11.38 |
| **5** | 115 | 17.69 |
| **No response** | 29 | 4.46 |

## Writing to your candidates by email
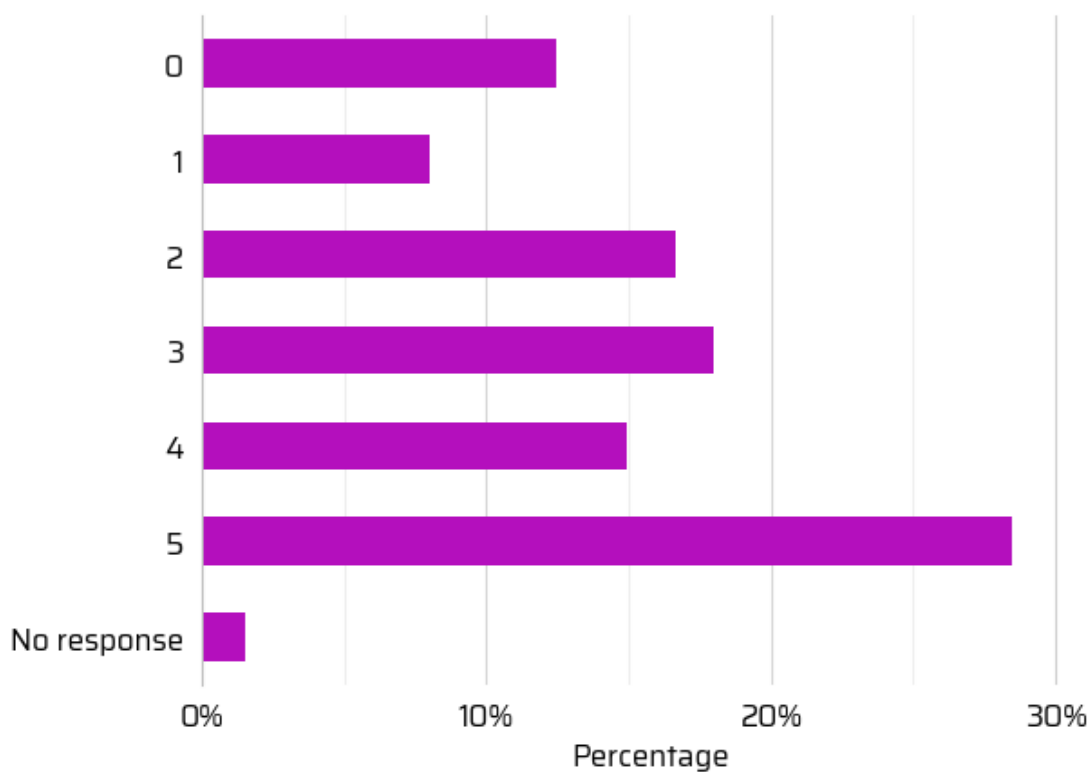


Figure 5: Level of confidence for writing to your candidates by email.

Table 5: Level of confidence for writing to your candidates by email.

| Level of confidence | Respondents | Percentage |
|---|---|---|
| **0** | 81 | 12.46 |
| **1** | 52 | 8.0 |
| **2** | 108 | 16.62 |
| **3** | 117 | 18.0 |
| **4** | 97 | 14.92 |
| **5** | 185 | 28.46 |
| **No response** | 10 | 1.54 |

## Speaking to the local press
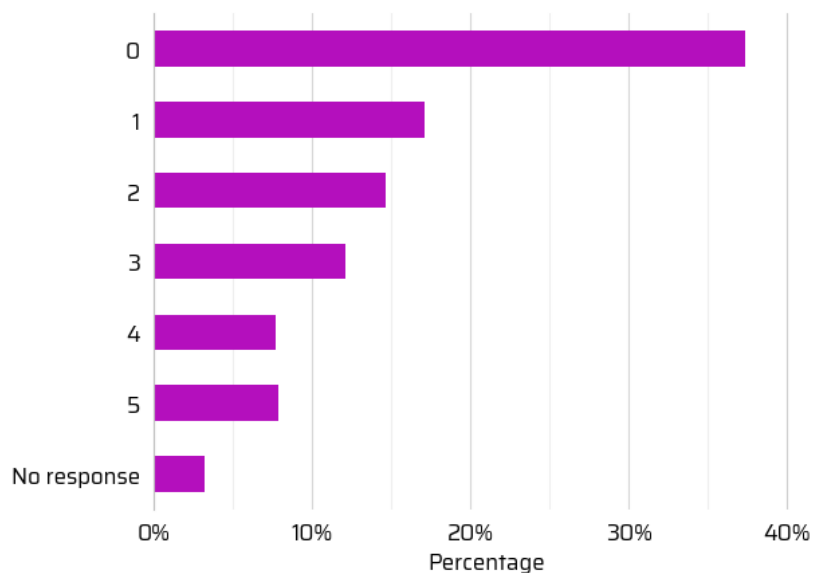


Figure 6: Level of confidence for speaking to the local press.

Table 6: Level of confidence for speaking to the local press.

| Level of confidence | Respondents | Percentage |
|---|---|---|
| **0** | 243 | 37.38 |
| **1** | 111 | 17.08 |
| **2** | 95 | 14.62 |
| **3** | 79 | 12.15 |
| **4** | 50 | 7.69 |
| **5** | 51 | 7.85 |
| **No response** | 21 | 3.23 |

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**Taking part in a stunt or protest**
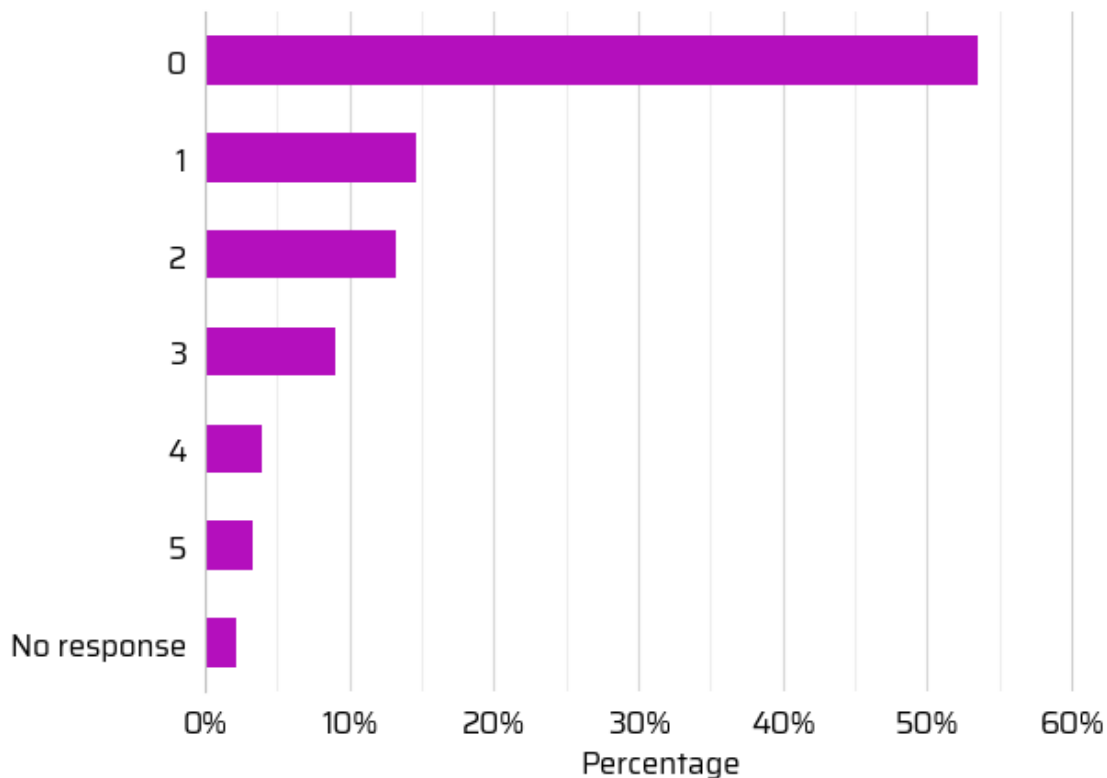


Figure 7: Level of confidence for taking part in a stunt or protest.

Table 7: Level of confidence for taking part in a stunt or protest.

| Level of confidence | Respondents | Percentage |
|---|---|---|
| **0** | 348 | 53.54 |
| **1** | 95 | 14.62 |
| **2** | 86 | 13.23 |
| **3** | 59 | 9.08 |
| **4** | 26 | 4.0 |
| **5** | 22 | 3.38 |
| **No response** | 14 | 2.15 |

# Medical appointments

## Access to medical appointments in the last eight weeks
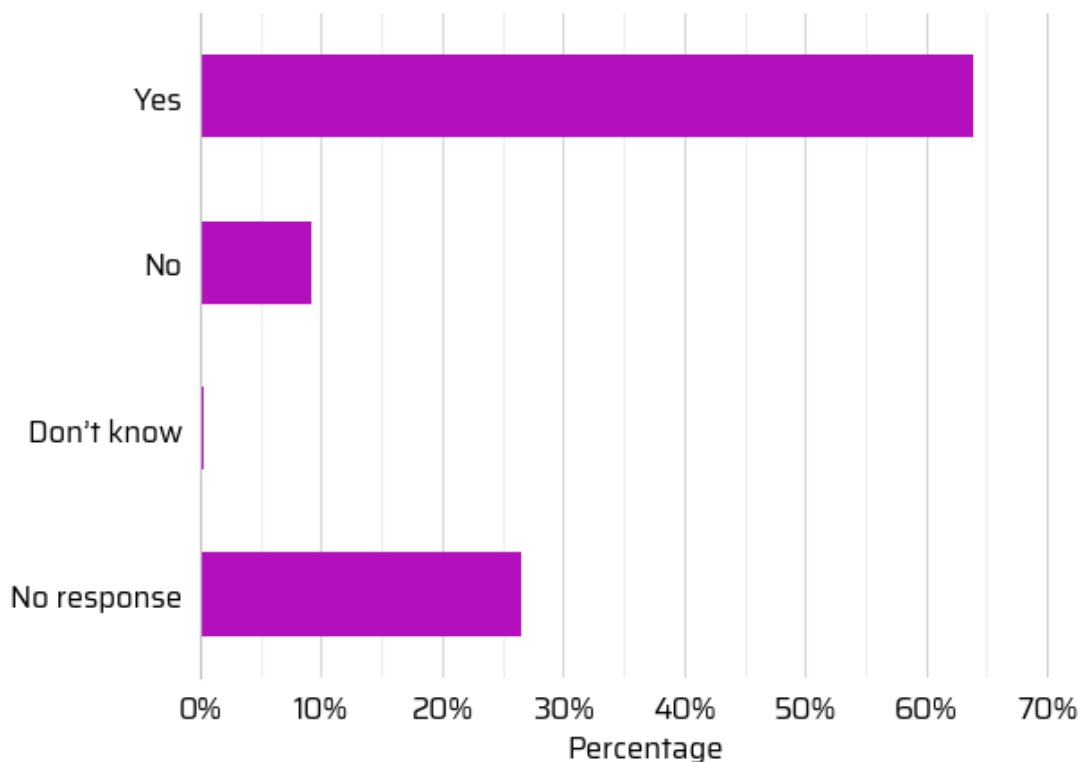


Figure 8: Access to medical appointments in the last eight weeks.

Table 8: Access to medical appointments in the last eight weeks.

| Appointments | Respondents | Percentage |
|---|---|---|
| Yes | 415 | 63.85 |
| No | 60 | 9.23 |
| Don't know | 2 | 0.31 |
| No response | 173 | 26.62 |

## Number of medical appointments
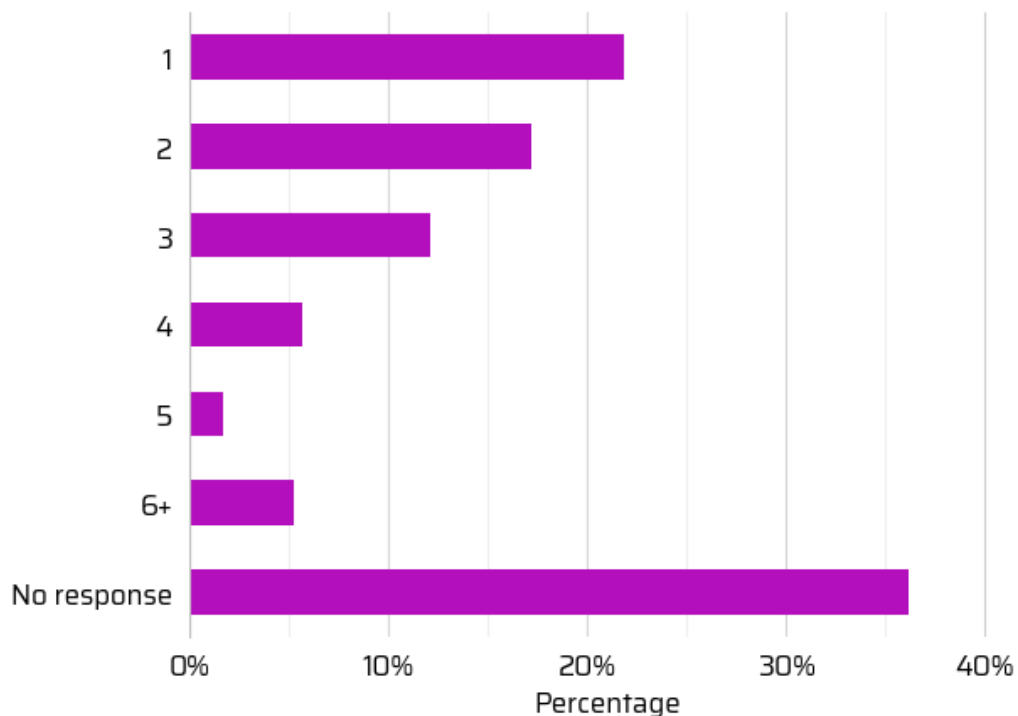


Figure 9: Number of medical appointments.

Table 9: Number of medical appointments.

| Number of appointments | Respondents | Percentage |
|---|---|---|
| **1** | 142 | 21.85 |
| **2** | 112 | 17.23 |
| **3** | 79 | 12.15 |
| **4** | 37 | 5.69 |
| **5** | 11 | 1.69 |
| **6+** | 34 | 5.23 |
| **No response** | 235 | 36.15 |

## Helpfulness of medical appointments
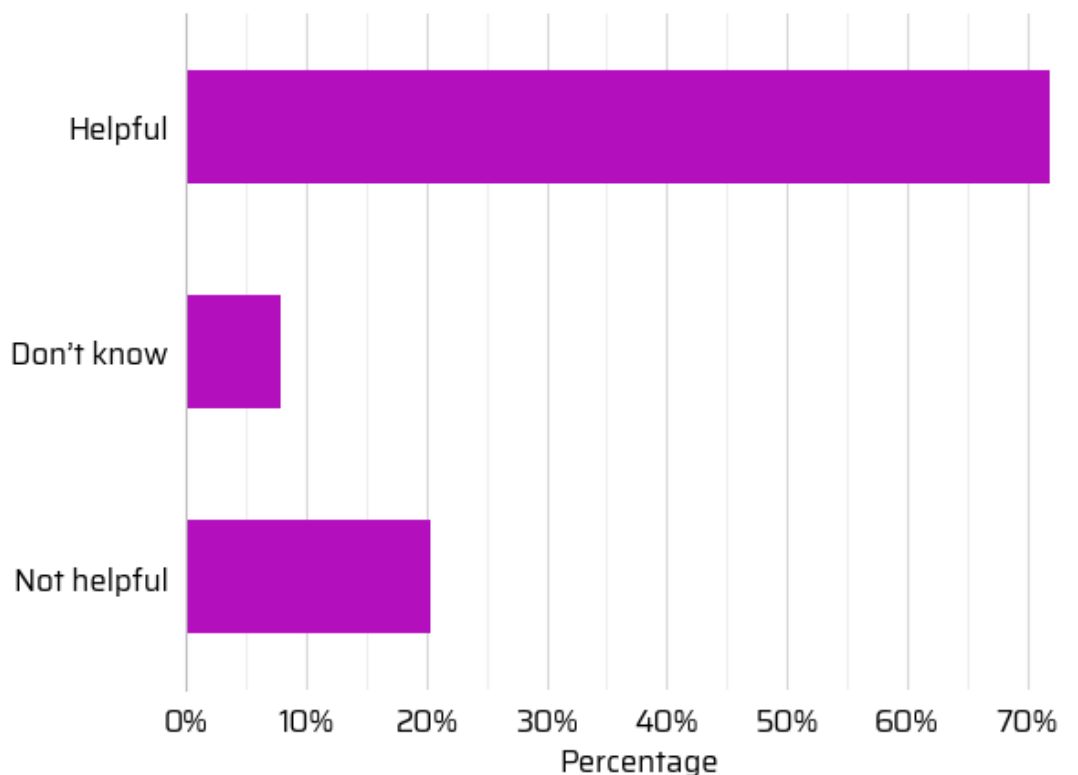


Figure 10: Helpfulness of medical appointments held in the last eight weeks.

Table 10: Helpfulness of medical appointments held in the last eight weeks.

| Helpfulness | Respondents | Percentage |
|---|---|---|
| **Helpful** | 759 | 71.81 |
| **Don't know** | 83 | 7.85 |
| **Not helpful** | 215 | 20.34 |

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
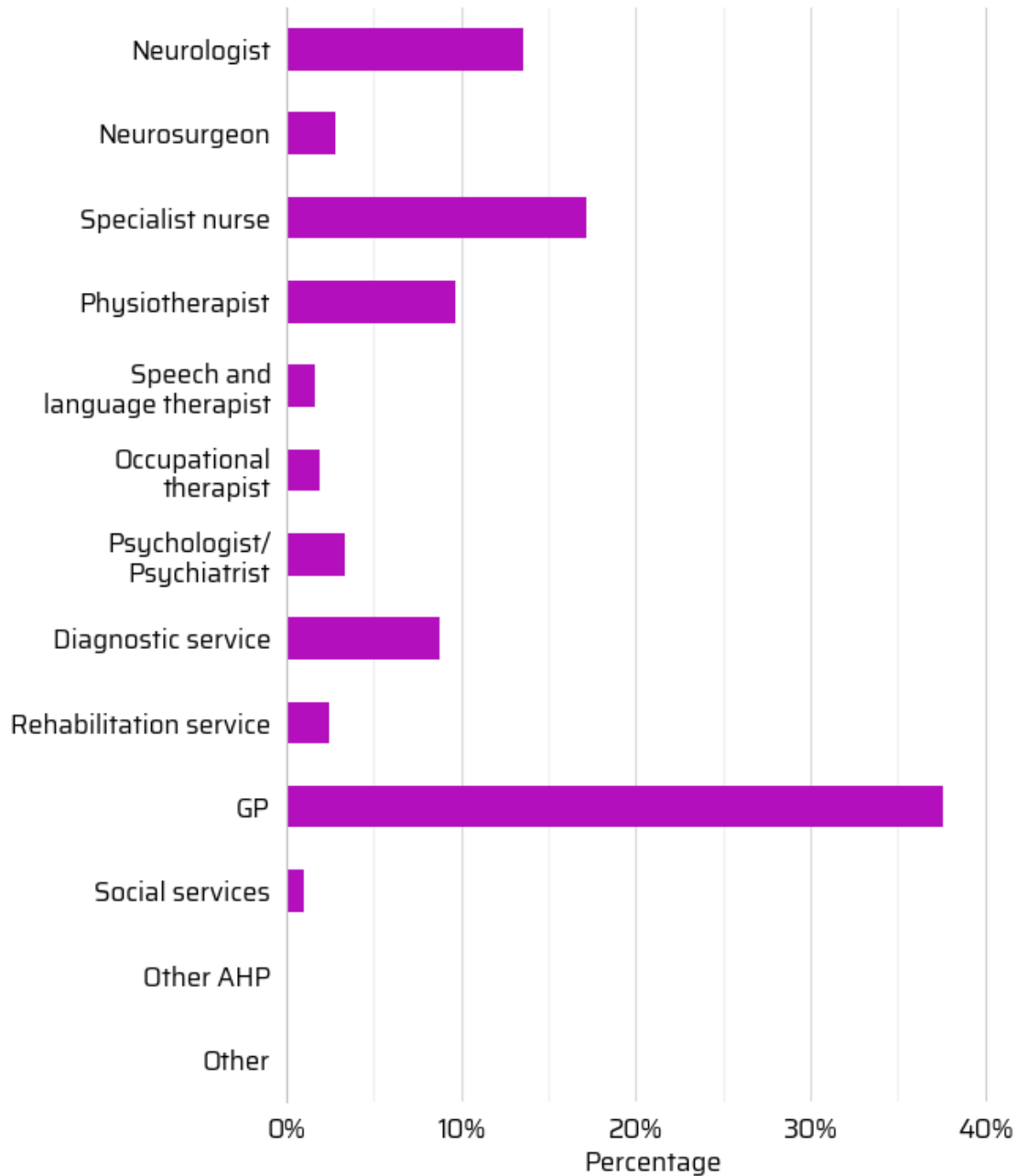


Figure 11: Speciality of the medical appointments held in the last eight weeks.

Table 11: Speciality of the medical appointments held in the last eight weeks.

| Specialty | Respondents | Percentage |
|---|---|---|
| **Neurologist** | 116 | 13.55 |
| **Neurosurgeon** | 24 | 2.8 |

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| | | |
|---|---|---|
| **Specialist nurse** | 147 | 17.17 |
| **Physiotherapist** | 83 | 9.7 |
| **Speech and language therapist** | 14 | 1.64 |
| **Occupational therapist** | 16 | 1.87 |
| **Psychologist/ Psychiatrist** | 29 | 3.39 |
| **Diagnostic service** | 75 | 8.76 |
| **Rehabilitation service** | 21 | 2.45 |
| **GP** | 322 | 37.62 |
| **Social services** | 9 | 1.05 |
| **Other AHP** | 0 | 0.0 |
| **Other** | 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
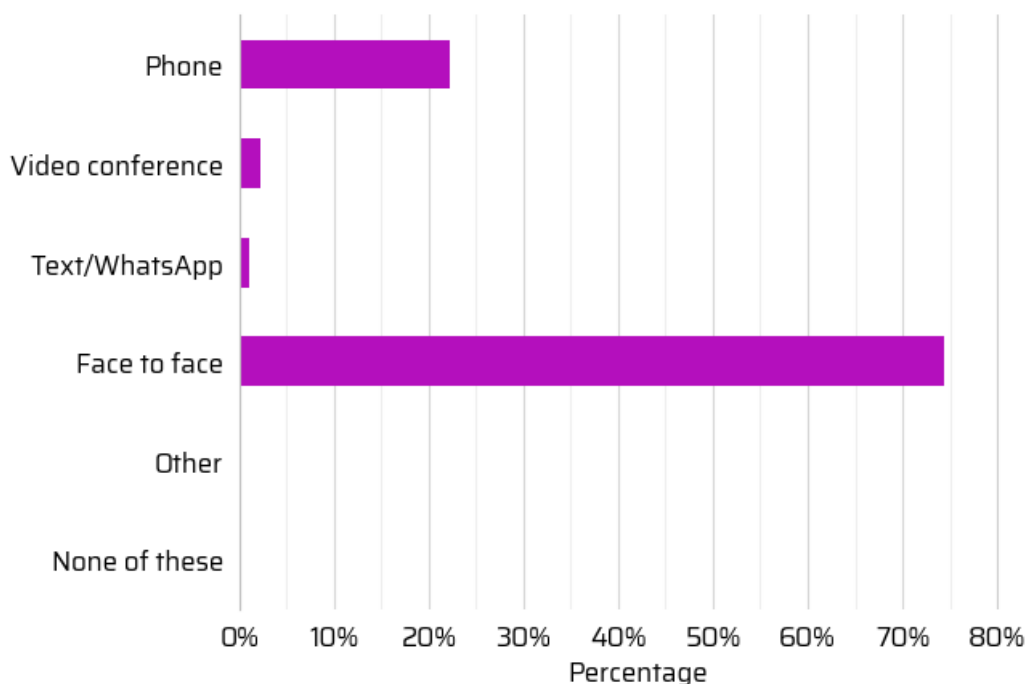


Figure 12: Mode of medical appointments completed in the last eight weeks.

Table 12: Mode of medical appointments completed in the last eight weeks.

| Mode | Respondents | Percentage |
| --- | --- | --- |
| **Phone** | 226 | 22.29 |
| **Video conference** | 23 | 2.27 |
| **Text/WhatsApp** | 11 | 1.08 |
| **Face to face** | 754 | 74.36 |
| **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
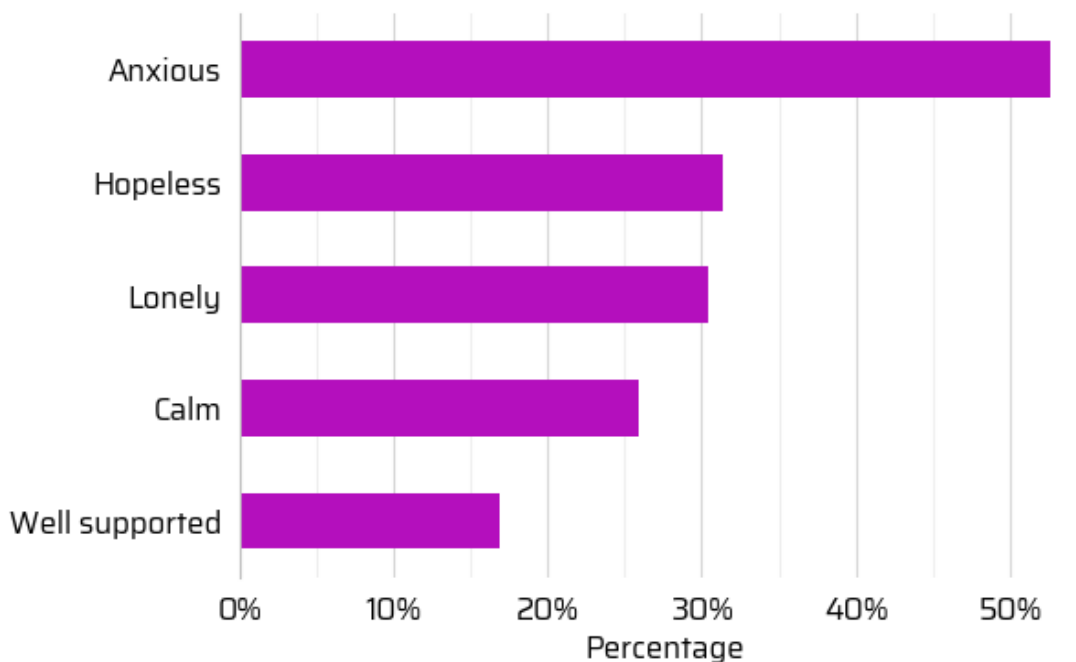


Figure 13: Feelings of the respondents at the time of the survey.

Table 13: Feelings of the respondents at the time of the survey.

| Feelings | Respondents | Percentage |
| --- | --- | --- |
| **Anxious** | 342 | 52.62 |
| **Hopeless** | 204 | 31.38 |
| **Lonely** | 198 | 30.46 |
| **Calm** | 168 | 25.85 |
| **Well supported** | 110 | 16.92 |

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.

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## Impact on quality of life
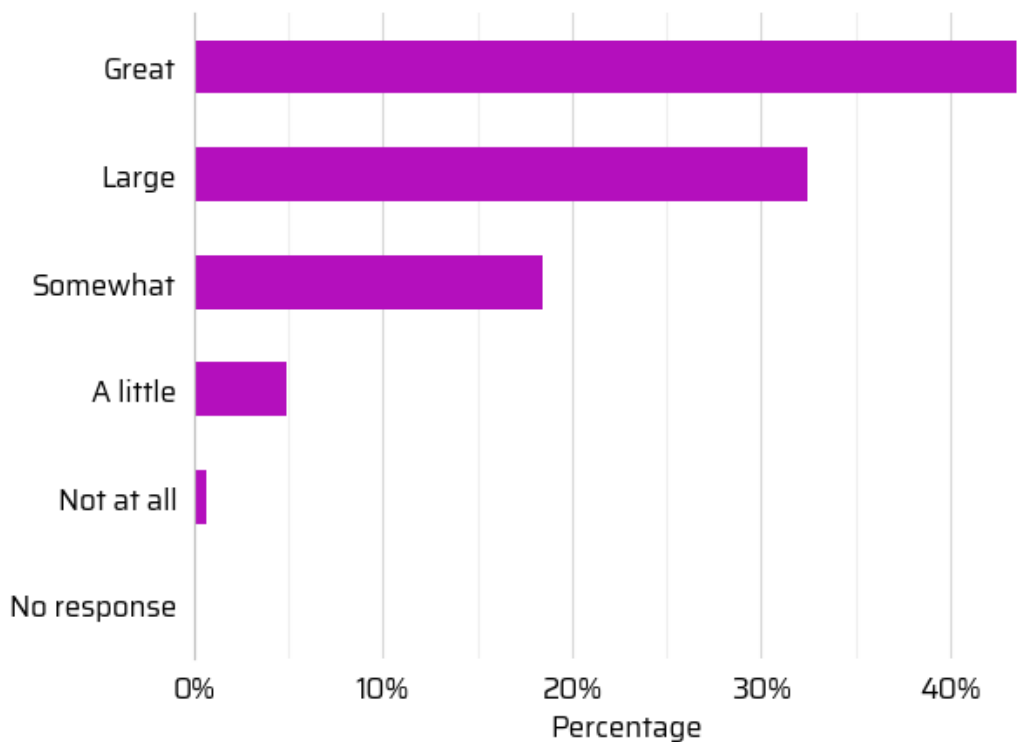


Figure 14: The extent to which neurological conditions affect the quality of life.

Table 14: The extent to which neurological conditions affect the quality of life.

| Impact | Respondents | Percentage |
|---|---|---|
| **Great** | 283 | 43.54 |
| **Large** | 211 | 32.46 |
| **Somewhat** | 120 | 18.46 |
| **A little** | 32 | 4.92 |
| **Not at all** | 4 | 0.62 |
| **No response** | 0 | 0.0 |

## Extent mental health needs were met.
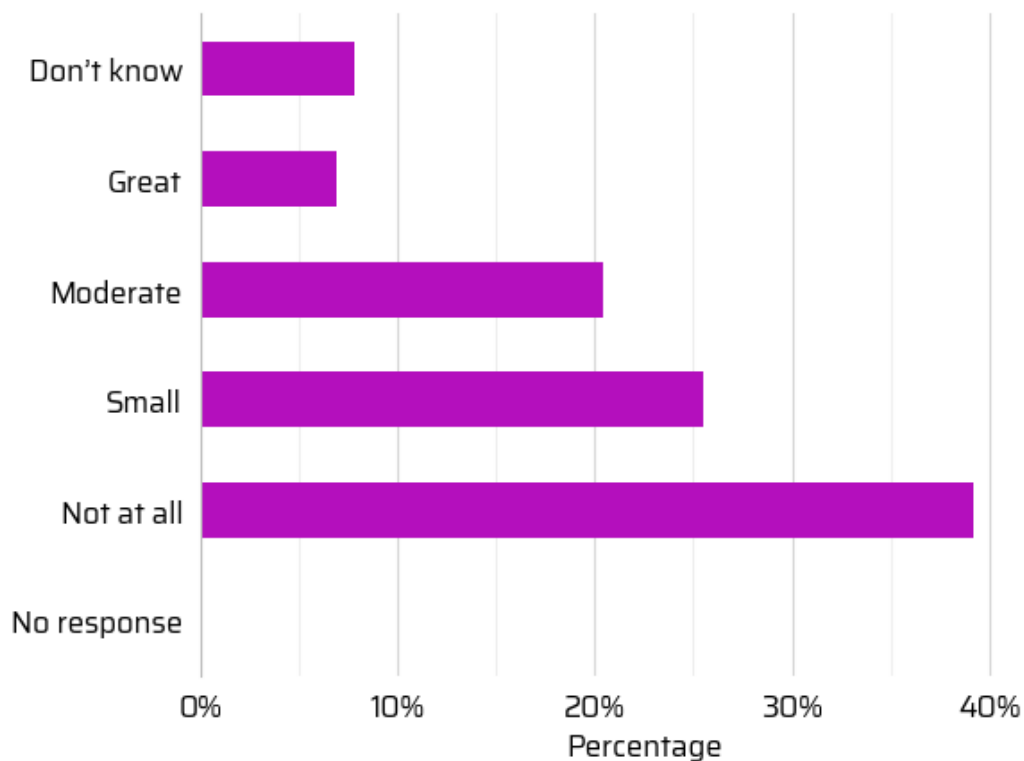


Figure 15: The extent to which respondents' mental health needs were met.

Table 15: The extent to which respondents' mental health needs were met.

| Needs met | Respondents | Percentage |
|---|---|---|
| Don't know | 51 | 7.85 |
| Great | 45 | 6.92 |
| Moderate | 133 | 20.46 |
| Small | 166 | 25.54 |
| Not at all | 255 | 39.23 |
| No response | 0 | 0.0 |

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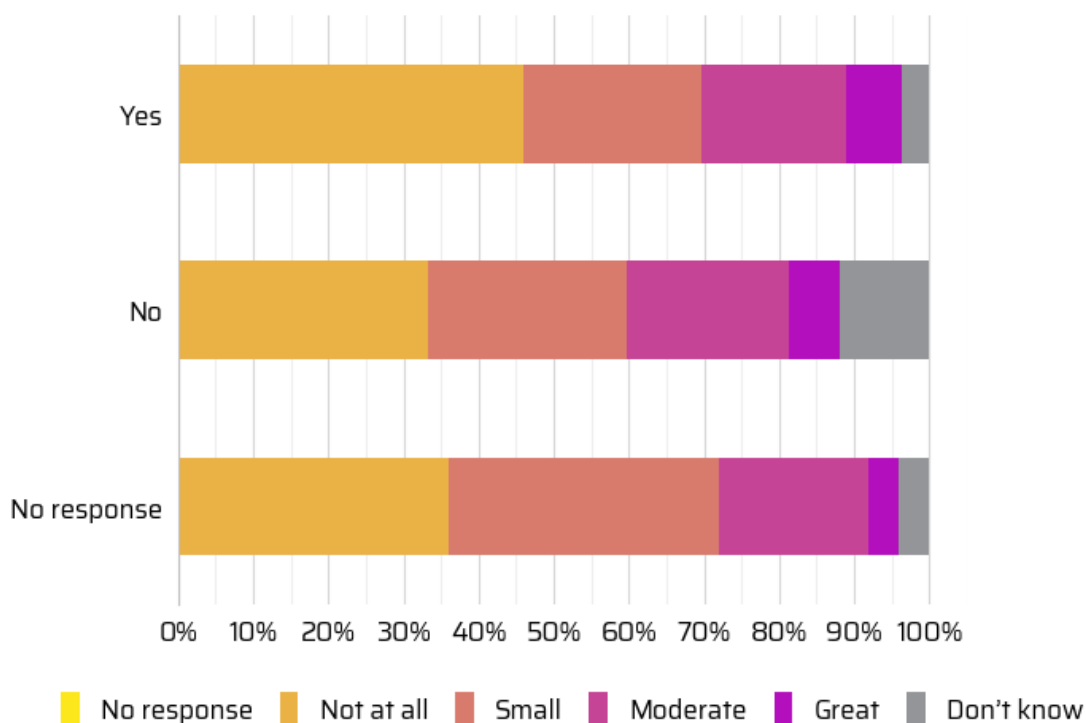


Figure 16: The extent to which respondents' mental health needs were met, broken down by whether diagnosed with multiple neurological conditions.

Table 16: 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 |
|---|---|---|---|
| **Yes** | Don't know | 11 | 3.67 |
| | Great | 22 | 7.33 |
| | Moderate | 58 | 19.33 |
| | Small | 71 | 23.67 |
| | Not at all | 138 | 46.0 |
| | No response | 0 | 0.0 |
| **No** | Don't know | 39 | 12.0 |
| | Great | 22 | 6.77 |

| | | | |
|---|---|---|---|
| | Moderate | 70 | 21.54 |
| | Small | 86 | 26.46 |
| | Not at all | 108 | 33.23 |
| | No response | 0 | 0.0 |
| | Don't know | 1 | 4.0 |
| | Great | 1 | 4.0 |
| **No response** | Moderate | 5 | 20.0 |
| | Small | 9 | 36.0 |
| | Not at all | 9 | 36.0 |
| | No response | 0 | 0.0 |

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



Figure 17: The extent to which respondents' mental health needs were met, broken down by age group.

Table 17: 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 | 0 | 0.0 |
| | Moderate | 0 | 0.0 |
| | Small | 0 | 0.0 |
| | Not at all | 1 | 100.0 |
| | No response | 0 | 0.0 |
| **18-24** | Don't know | 0 | 0.0 |
| | Great | 2 | 40.0 |
| | Moderate | 0 | 0.0 |
| | Small | 1 | 20.0 |
| | Not at all | 2 | 40.0 |
| | No response | 0 | 0.0 |
| **25-34** | Don't know | 2 | 4.08 |
| | Great | 4 | 8.16 |
| | Moderate | 8 | 16.33 |
| | Small | 21 | 42.86 |
| | Not at all | 14 | 28.57 |
| | No response | 0 | 0.0 |
| **35-44** | Don't know | 1 | 1.64 |
| | Great | 2 | 3.28 |
| | Moderate | 10 | 16.39 |
| | Small | 14 | 22.95 |
| | Not at all | 34 | 55.74 |
| | No response | 0 | 0.0 |
| **45-54** | Don't know | 2 | 1.53 |
| | Great | 7 | 5.34 |
| | Moderate | 35 | 26.72 |
| | Small | 39 | 29.77 |
| | Not at all | 48 | 36.64 |

| | | | |
|---|---|---|---|
| | No response | 0 | 0.0 |
| | Don't know | 14 | 7.14 |
| | Great | 10 | 5.1 |
| **55-64** | Moderate | 37 | 18.88 |
| | Small | 49 | 25.0 |
| | Not at all | 86 | 43.88 |
| | No response | 0 | 0.0 |
| | Don't know | 10 | 13.7 |
| | Great | 2 | 2.74 |
| **65-69** | Moderate | 17 | 23.29 |
| | Small | 15 | 20.55 |
| | Not at all | 29 | 39.73 |
| | No response | 0 | 0.0 |
| | Don't know | 22 | 16.42 |
| | Great | 18 | 13.43 |
| **70+** | Moderate | 26 | 19.4 |
| | Small | 27 | 20.15 |
| | Not at all | 41 | 30.6 |
| | No response | 0 | 0.0 |
| | Don't know | 0 | 0.0 |
| | Great | 0 | 0.0 |
| **No response** | 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 18: The extent to which respondents' mental health needs were met, broken down by gender.

Table 18: The extent to which respondents' mental health needs were met, broken down by gender.

| Gender | Needs met | Respondents | Percentage |
|--------|-----------|-------------|------------|
| | Don't know | 35 | 7.13 |
| | Great | 30 | 6.11 |
| | Moderate | 106 | 21.59 |
| **Female** | Small | 121 | 24.64 |
| | Not at all | 199 | 40.53 |
| | No response | 0 | 0.0 |
| | Don't know | 16 | 10.88 |
| | Great | 14 | 9.52 |
| **Male** | Moderate | 26 | 17.69 |
| | Small | 38 | 25.85 |
| | Not at all | 53 | 36.05 |

| | | | |
|---|---|---|---|
| | No response | 0 | 0.0 |
| **Prefer not to say** | Don't know | 0 | 0.0 |
| | Great | 1 | 20.0 |
| | Moderate | 1 | 20.0 |
| | Small | 1 | 20.0 |
| | Not at all | 2 | 40.0 |
| | No response | 0 | 0.0 |
| **Prefer to self-describe** | Don't know | 0 | 0.0 |
| | Great | 0 | 0.0 |
| | Moderate | 0 | 0.0 |
| | Small | 6 | 85.71 |
| | Not at all | 1 | 14.29 |
| | No response | 0 | 0.0 |
| **No response** | 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 |

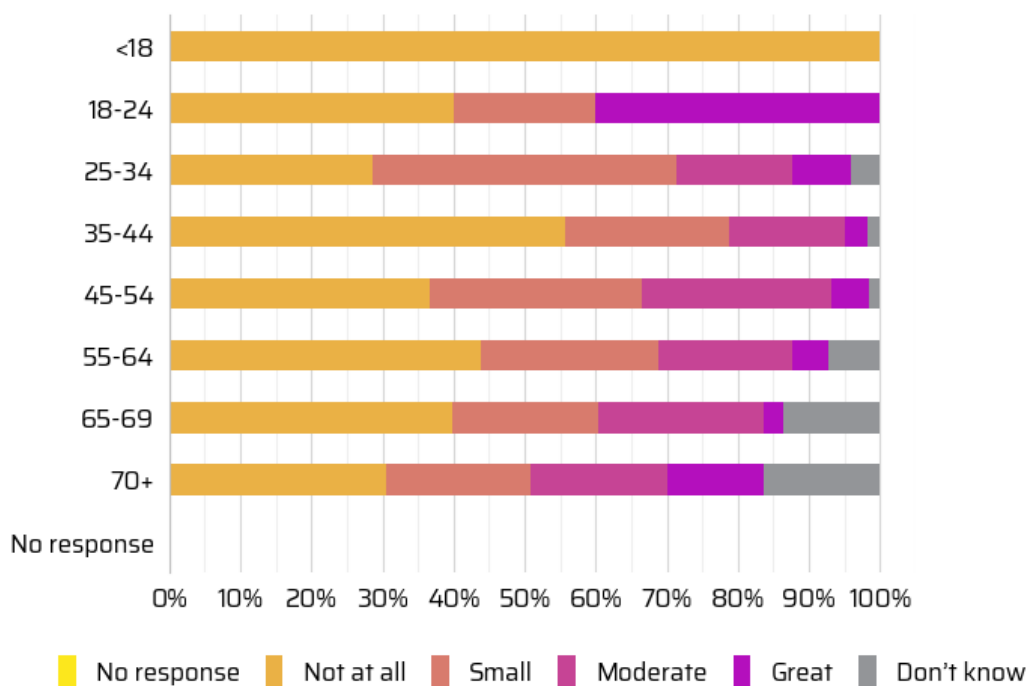## Extent mental health needs were met by employment status.



Figure 19: The extent to which respondents' mental health needs were met, broken down by employment status.

Table 19: 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 | 4 | 5.33 |
| | Great | 4 | 5.33 |
| | Moderate | 19 | 25.33 |
| | Small | 20 | 26.67 |
| | Not at all | 28 | 37.33 |
| | No response | 0 | 0.0 |
| **Employed (part-time)** | Don't know | 4 | 6.78 |
| | Great | 1 | 1.69 |
| | Moderate | 9 | 15.25 |
| | Small | 23 | 38.98 |
| | Not at all | 22 | 37.29 |

| | | | |
|---|---|---|---|
| | No response | 0 | 0.0 |
| | Don't know | 0 | 0.0 |
| | Great | 0 | 0.0 |
| **Homemaker** | Moderate | 5 | 41.67 |
| | Small | 3 | 25.0 |
| | Not at all | 4 | 33.33 |
| | No response | 0 | 0.0 |
| | Don't know | 0 | 0.0 |
| | Great | 0 | 0.0 |
| **Other** | Moderate | 0 | 0.0 |
| | Small | 0 | 0.0 |
| | Not at all | 0 | 0.0 |
| | No response | 0 | 0.0 |
| | Don't know | 0 | 0.0 |
| | Great | 3 | 27.27 |
| **Out of work** | Moderate | 1 | 9.09 |
| | Small | 6 | 54.55 |
| | Not at all | 1 | 9.09 |
| | No response | 0 | 0.0 |
| | Don't know | 0 | 0.0 |
| | Great | 0 | 0.0 |
| **Prefer not to say** | Moderate | 1 | 33.33 |
| | Small | 1 | 33.33 |
| | Not at all | 1 | 33.33 |
| | No response | 0 | 0.0 |
| | Don't know | 31 | 13.14 |
| **Retired** | Great | 23 | 9.75 |
| | Moderate | 52 | 22.03 |

| | | | |
|---|---|---|---|
| | Small | 49 | 20.76 |
| | Not at all | 81 | 34.32 |
| | No response | 0 | 0.0 |
| **Self-employed (full-time)** | Don't know | 2 | 28.57 |
| | Great | 0 | 0.0 |
| | Moderate | 0 | 0.0 |
| | Small | 1 | 14.29 |
| | Not at all | 4 | 57.14 |
| | No response | 0 | 0.0 |
| **Self-employed (part-time)** | Don't know | 1 | 4.0 |
| | Great | 2 | 8.0 |
| | Moderate | 6 | 24.0 |
| | Small | 8 | 32.0 |
| | Not at all | 8 | 32.0 |
| | No response | 0 | 0.0 |
| **Student** | Don't know | 0 | 0.0 |
| | Great | 1 | 20.0 |
| | Moderate | 0 | 0.0 |
| | Small | 0 | 0.0 |
| | Not at all | 4 | 80.0 |
| | No response | 0 | 0.0 |
| **Unable to work** | Don't know | 9 | 4.35 |
| | Great | 11 | 5.31 |
| | Moderate | 39 | 18.84 |
| | Small | 53 | 25.6 |
| | Not at all | 95 | 45.89 |
| | No response | 0 | 0.0 |
| **No response** | Don't know | 0 | 0.0 |

| | | |
|---|---|---|
| Great | 0 | 0.0 |
| Moderate | 1 | 10.0 |
| Small | 2 | 20.0 |
| Not at all | 7 | 70.0 |
| No response | 0 | 0.0 |

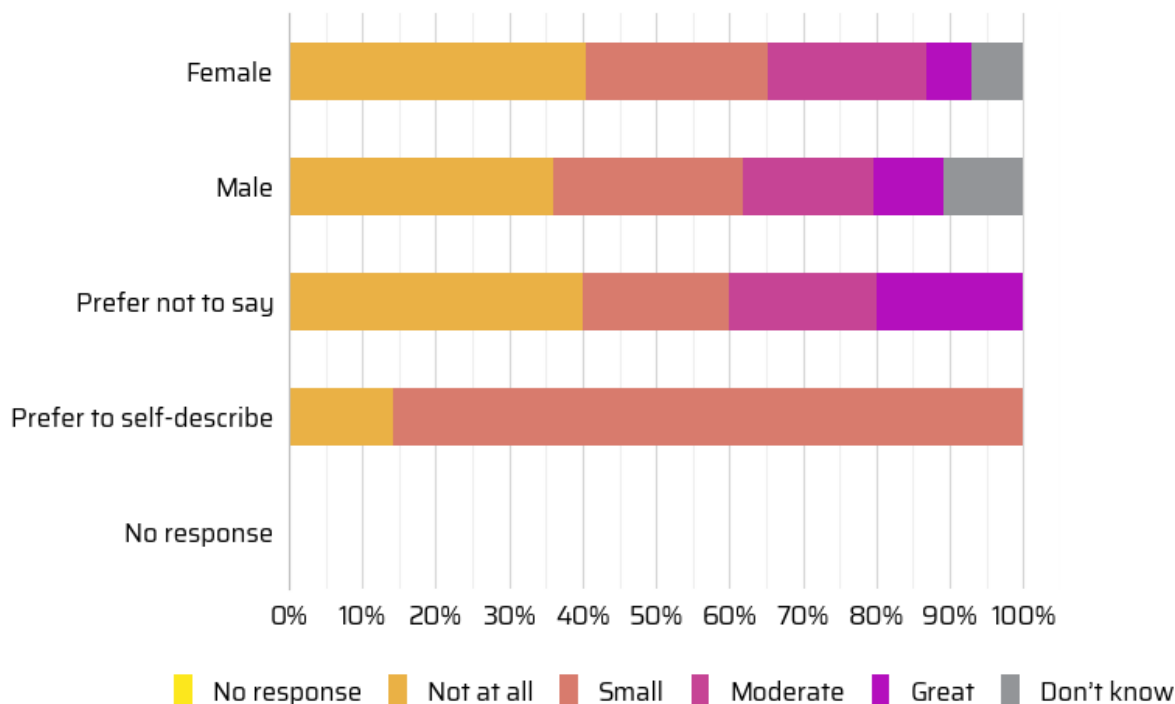## Extent mental health needs were met by number of dependents
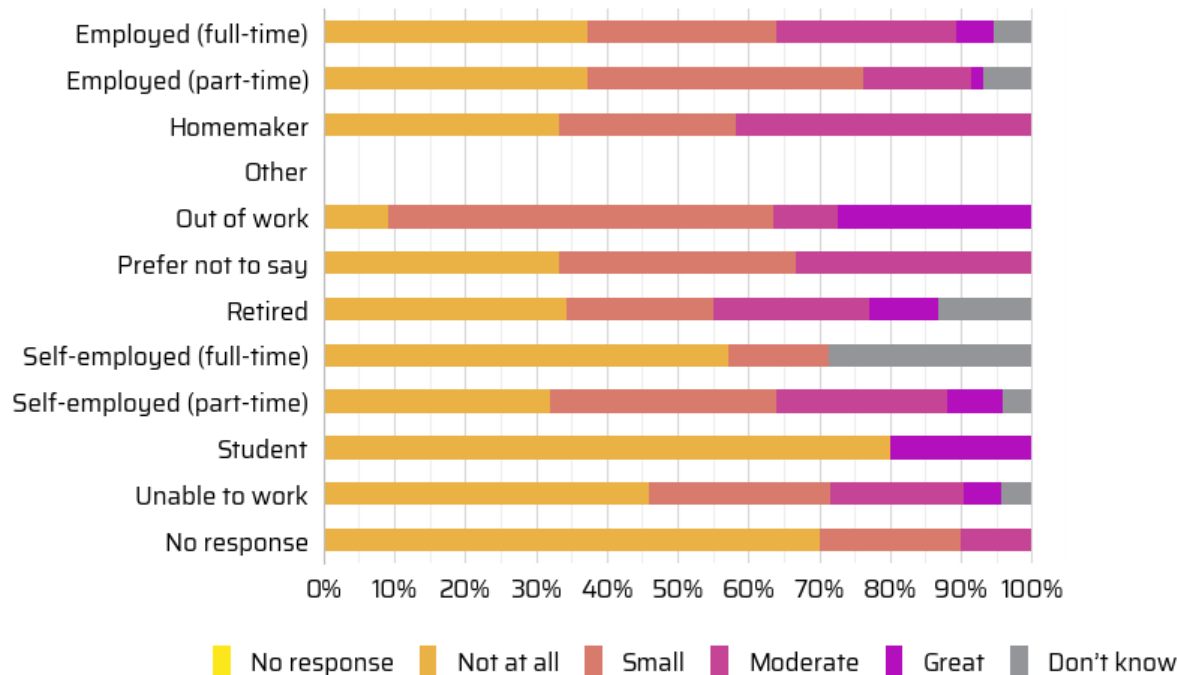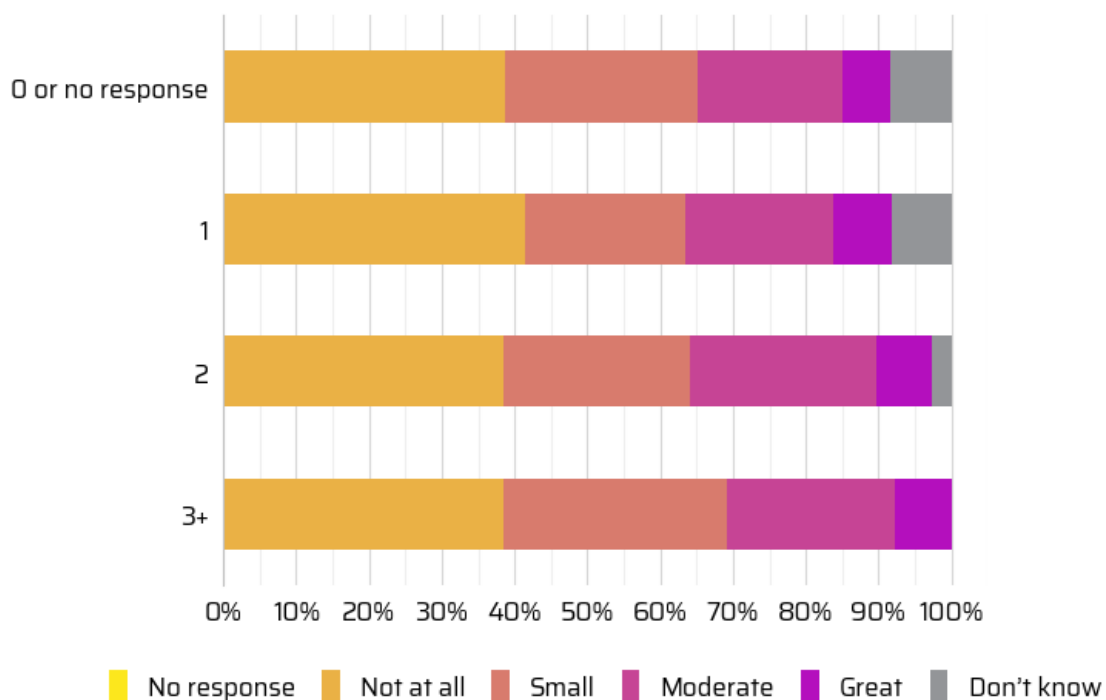


Figure 20: The extent to which respondents' mental health needs were met, broken down by number of dependents.

Table 20: The extent to which respondents' mental health needs were met, broken down by number of dependents.

| Number of dependents | Needs met | Respondents | Percentage |
|---|---|---|---|
| **0 or no response** | Don't know | 40 | 8.42 |
| | Great | 31 | 6.53 |

| | | | |
|---|---|---|---|
| | Moderate | 95 | 20.0 |
| | Small | 125 | 26.32 |
| | Not at all | 184 | 38.74 |
| | No response | 0 | 0.0 |
| **1** | Don't know | 10 | 8.13 |
| | Great | 10 | 8.13 |
| | Moderate | 25 | 20.33 |
| | Small | 27 | 21.95 |
| | Not at all | 51 | 41.46 |
| | No response | 0 | 0.0 |
| **2** | Don't know | 1 | 2.56 |
| | Great | 3 | 7.69 |
| | Moderate | 10 | 25.64 |
| | Small | 10 | 25.64 |
| | Not at all | 15 | 38.46 |
| | No response | 0 | 0.0 |
| **3+** | Don't know | 0 | 0.0 |
| | Great | 1 | 7.69 |
| | Moderate | 3 | 23.08 |
| | Small | 4 | 30.77 |
| | Not at all | 5 | 38.46 |
| | No response | 0 | 0.0 |

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



Figure 21: Frequency that NHS A&E/emergency services were sought in the last eight weeks.

Table 21: Frequency that NHS A&E/emergency services were sought in the last eight weeks.

| Frequency | Respondents | Percentage |
| --- | --- | --- |
| **0** | 590 | 90.77 |
| **1-2** | 54 | 8.31 |
| **3-5** | 3 | 0.46 |
| **5+** | 3 | 0.46 |
| **No response** | 0 | 0.0 |

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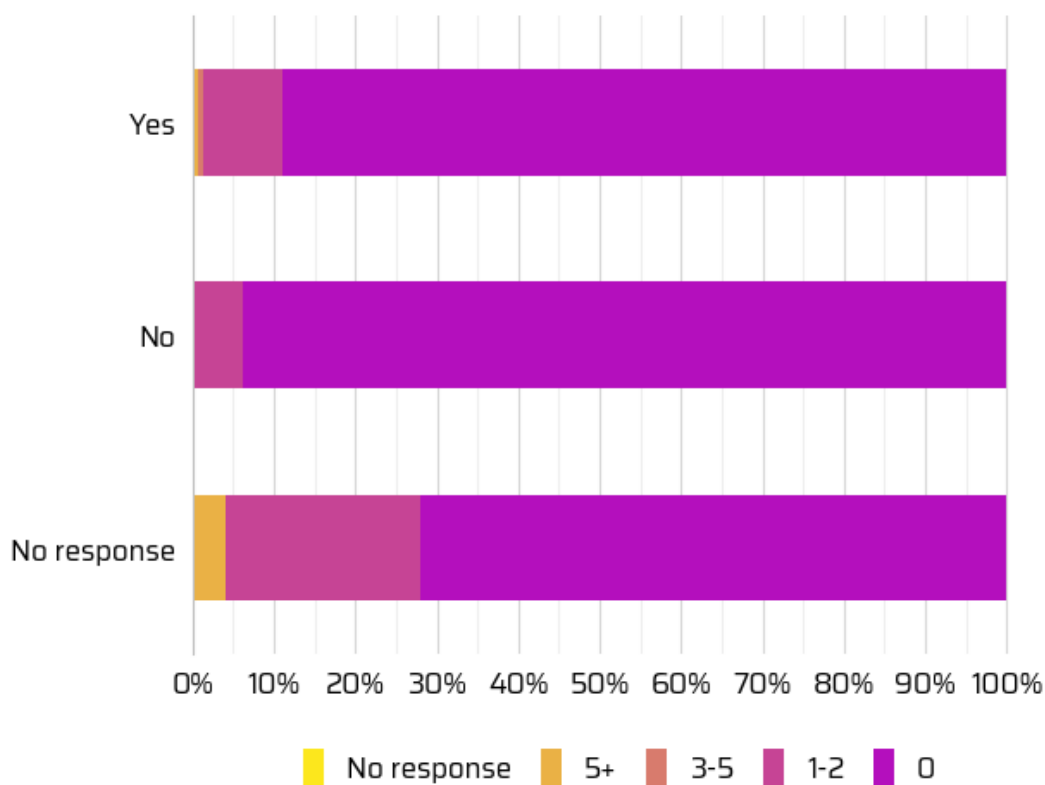


Figure 22: Frequency that NHS A&E/emergency services were sought, broken down by whether diagnosed with multiple neurological conditions.

Table 22: 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 | 267 | 89.0 |
| | 1-2 | 29 | 9.67 |
| | 3-5 | 2 | 0.67 |
| | 5+ | 2 | 0.67 |
| | No response | 0 | 0.0 |
| **No** | 0 | 305 | 93.85 |

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|  |  |  |  |
|---|---|---|---|
|  | 1-2 | 19 | 5.85 |
|  | 3-5 | 1 | 0.31 |
|  | 5+ | 0 | 0.0 |
|  | No response | 0 | 0.0 |
| **No response** | 0 | 18 | 72.0 |
|  | 1-2 | 6 | 24.0 |
|  | 3-5 | 0 | 0.0 |
|  | 5+ | 1 | 4.0 |
|  | No response | 0 | 0.0 |

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



Figure 23: Frequency that NHS A&E/emergency services were sought, broken down by age group.

Table 23: Frequency that NHS A&E/emergency services were sought, broken down by age group.

| Age | Frequency | Respondents | Percentage |
|---|---|---|---|
| **<18** | 0 | 1 | 100.0 |
| | 1-2 | 0 | 0.0 |
| | 3-5 | 0 | 0.0 |
| | 5+ | 0 | 0.0 |
| | No response | 0 | 0.0 |
| **18-24** | 0 | 5 | 100.0 |
| | 1-2 | 0 | 0.0 |
| | 3-5 | 0 | 0.0 |

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| | | | |
|---|---|---|---|
| | 5+ | 0 | 0.0 |
| | No response | 0 | 0.0 |
| **25-34** | 0 | 45 | 91.84 |
| | 1-2 | 2 | 4.08 |
| | 3-5 | 1 | 2.04 |
| | 5+ | 1 | 2.04 |
| | No response | 0 | 0.0 |
| **35-44** | 0 | 55 | 90.16 |
| | 1-2 | 5 | 8.2 |
| | 3-5 | 0 | 0.0 |
| | 5+ | 1 | 1.64 |
| | No response | 0 | 0.0 |
| **45-54** | 0 | 112 | 85.5 |
| | 1-2 | 18 | 13.74 |
| | 3-5 | 0 | 0.0 |
| | 5+ | 1 | 0.76 |
| | No response | 0 | 0.0 |
| **55-64** | 0 | 181 | 92.35 |
| | 1-2 | 14 | 7.14 |
| | 3-5 | 1 | 0.51 |
| | 5+ | 0 | 0.0 |
| | No response | 0 | 0.0 |
| **65-69** | 0 | 69 | 94.52 |
| | 1-2 | 4 | 5.48 |
| | 3-5 | 0 | 0.0 |

|  |  |  |  |
|---|---|---|---|
|  | 5+ | 0 | 0.0 |
|  | No response | 0 | 0.0 |
| **70+** | 0 | 122 | 91.04 |
|  | 1-2 | 11 | 8.21 |
|  | 3-5 | 1 | 0.75 |
|  | 5+ | 0 | 0.0 |
|  | No response | 0 | 0.0 |
| **No response** | 0 | 0 | 0.0 |
|  | 1-2 | 0 | 0.0 |
|  | 3-5 | 0 | 0.0 |
|  | 5+ | 0 | 0.0 |
|  | No response | 0 | 0.0 |

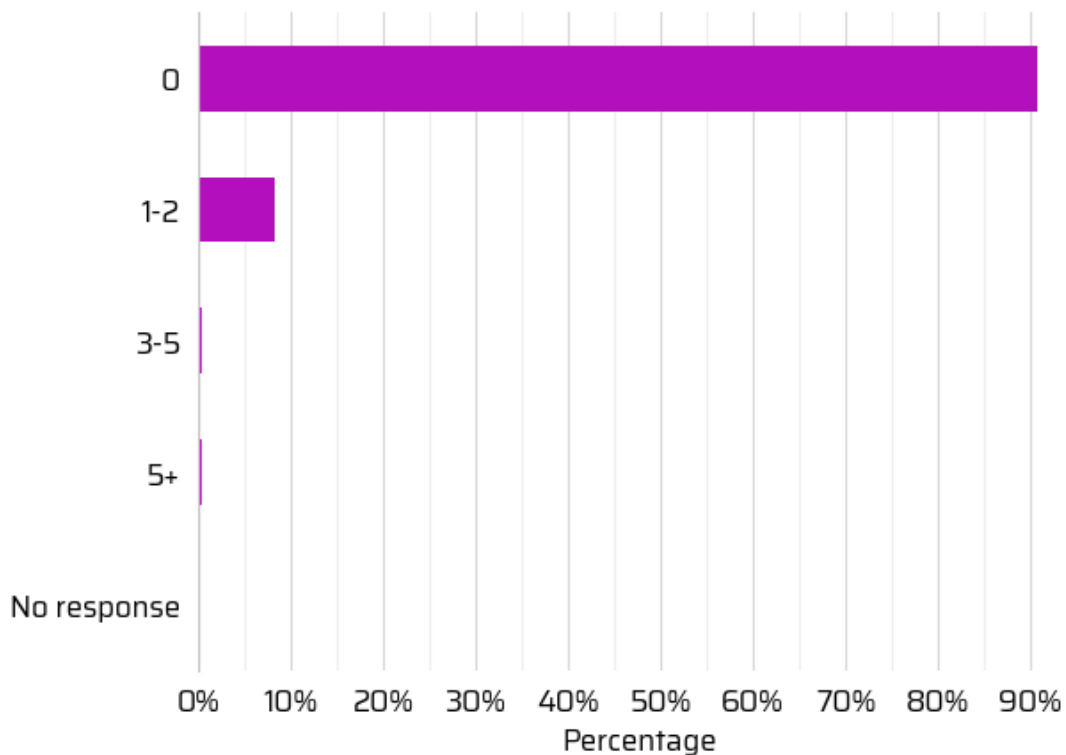## Frequency NHS A&E/emergency services were sought by gender.



Figure 24: Frequency that NHS A&E/emergency services were sought, broken down by gender.

Table 24: Frequency that NHS A&E/emergency services were sought, broken down by gender.

| Gender | Frequency | Respondents | Percentage |
|---|---|---|---|
| **Female** | 0 | 441 | 89.82 |
| | 1-2 | 44 | 8.96 |
| | 3-5 | 3 | 0.61 |
| | 5+ | 3 | 0.61 |
| | No response | 0 | 0.0 |
| **Male** | 0 | 138 | 93.88 |
| | 1-2 | 9 | 6.12 |
| | 3-5 | 0 | 0.0 |
| | 5+ | 0 | 0.0 |

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| | | | |
|---|---|---|---|
| | No response | 0 | 0.0 |
| **Prefer not to say** | 0 | 4 | 80.0 |
| | 1-2 | 1 | 20.0 |
| | 3-5 | 0 | 0.0 |
| | 5+ | 0 | 0.0 |
| | No response | 0 | 0.0 |
| **Prefer to self-describe** | 0 | 7 | 100.0 |
| | 1-2 | 0 | 0.0 |
| | 3-5 | 0 | 0.0 |
| | 5+ | 0 | 0.0 |
| | No response | 0 | 0.0 |
| **No response** | 0 | 0 | 0.0 |
| | 1-2 | 0 | 0.0 |
| | 3-5 | 0 | 0.0 |
| | 5+ | 0 | 0.0 |
| | No response | 0 | 0.0 |

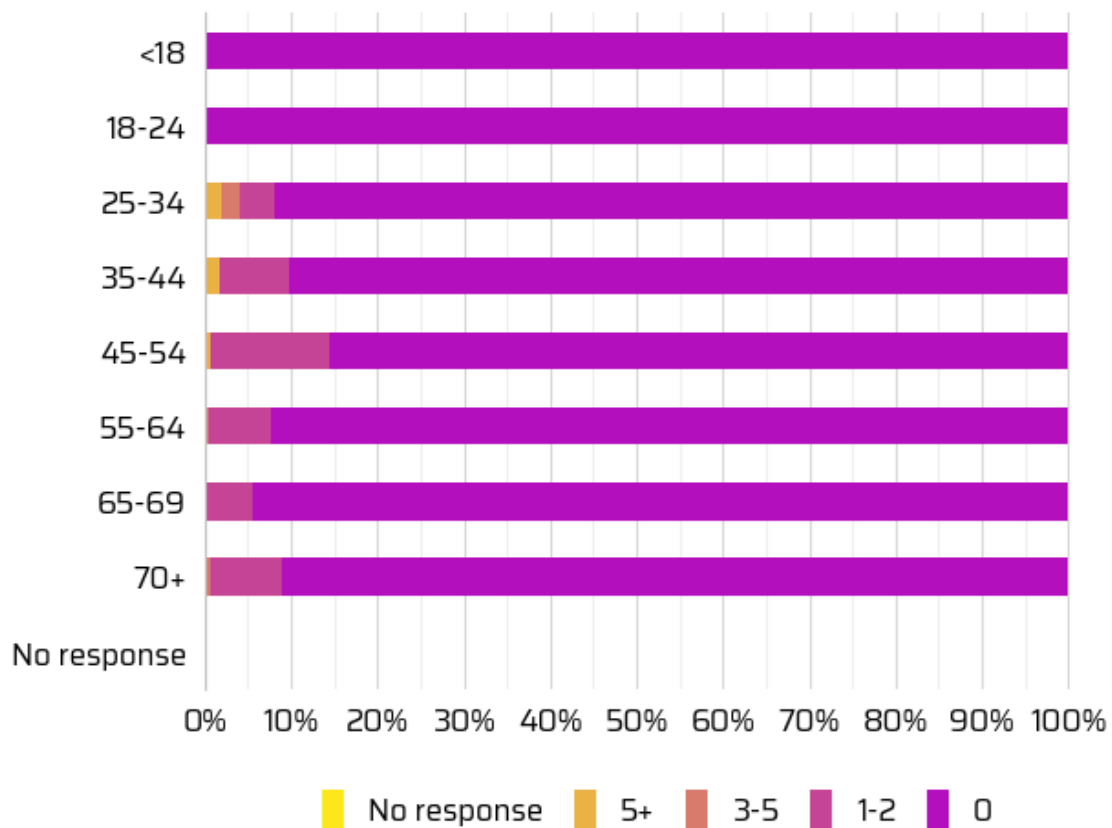# Frequency NHS A&E/emergency services were sought by employment status.



Figure 25: Frequency that NHS A&E/emergency services were sought, broken down by employment status.

Table 25: Frequency that NHS A&E/emergency services were sought, broken down by employment status.

| Employment status | Frequency | Respondents | Percentage |
|---|---|---|---|
| | 0 | 64 | 85.33 |
| | 1-2 | 9 | 12.0 |
| Employed (full-time) | 3-5 | 1 | 1.33 |
| | 5+ | 1 | 1.33 |
| | No response | 0 | 0.0 |
| Employed (part-time) | 0 | 58 | 98.31 |
| | 1-2 | 1 | 1.69 |
| | 3-5 | 0 | 0.0 |

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| | | | |
|---|---|---|---|
| | 5+ | 0 | 0.0 |
| | No response | 0 | 0.0 |
| **Homemaker** | 0 | 12 | 100.0 |
| | 1-2 | 0 | 0.0 |
| | 3-5 | 0 | 0.0 |
| | 5+ | 0 | 0.0 |
| | No response | 0 | 0.0 |
| **Other** | 0 | 0 | 0.0 |
| | 1-2 | 0 | 0.0 |
| | 3-5 | 0 | 0.0 |
| | 5+ | 0 | 0.0 |
| | No response | 0 | 0.0 |
| **Out of work** | 0 | 10 | 90.91 |
| | 1-2 | 1 | 9.09 |
| | 3-5 | 0 | 0.0 |
| | 5+ | 0 | 0.0 |
| | No response | 0 | 0.0 |
| **Prefer not to say** | 0 | 2 | 66.67 |
| | 1-2 | 1 | 33.33 |
| | 3-5 | 0 | 0.0 |
| | 5+ | 0 | 0.0 |
| | No response | 0 | 0.0 |
| **Retired** | 0 | 219 | 92.8 |
| | 1-2 | 17 | 7.2 |
| | 3-5 | 0 | 0.0 |

| | | | |
|---|---|---|---|
| | 5+ | 0 | 0.0 |
| | No response | 0 | 0.0 |
| **Self-employed (full-time)** | 0 | 6 | 85.71 |
| | 1-2 | 1 | 14.29 |
| | 3-5 | 0 | 0.0 |
| | 5+ | 0 | 0.0 |
| | No response | 0 | 0.0 |
| **Self-employed (part-time)** | 0 | 23 | 92.0 |
| | 1-2 | 1 | 4.0 |
| | 3-5 | 1 | 4.0 |
| | 5+ | 0 | 0.0 |
| | No response | 0 | 0.0 |
| **Student** | 0 | 4 | 80.0 |
| | 1-2 | 1 | 20.0 |
| | 3-5 | 0 | 0.0 |
| | 5+ | 0 | 0.0 |
| | No response | 0 | 0.0 |
| **Unable to work** | 0 | 184 | 88.89 |
| | 1-2 | 20 | 9.66 |
| | 3-5 | 1 | 0.48 |
| | 5+ | 2 | 0.97 |
| | No response | 0 | 0.0 |
| **No response** | 0 | 8 | 80.0 |
| | 1-2 | 2 | 20.0 |

| | | |
|---|---|---|
| 3-5 | 0 | 0.0 |
| 5+ | 0 | 0.0 |
| No response | 0 | 0.0 |

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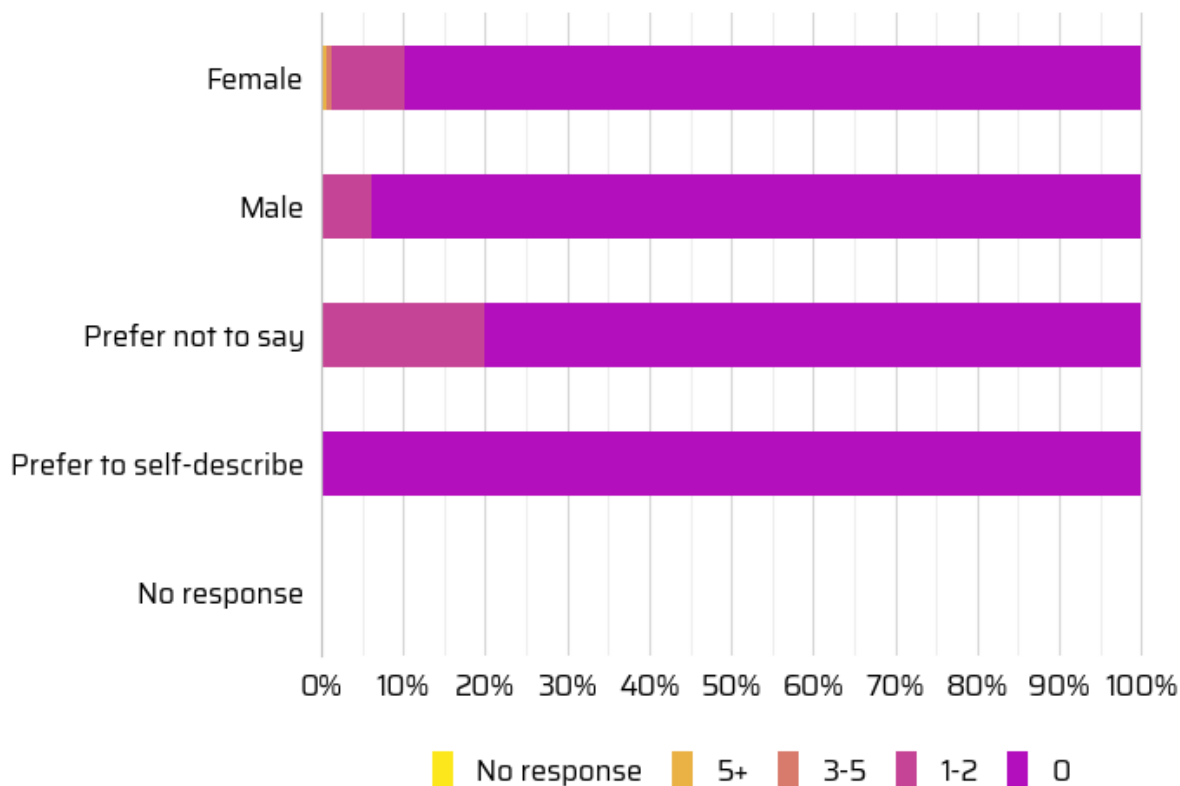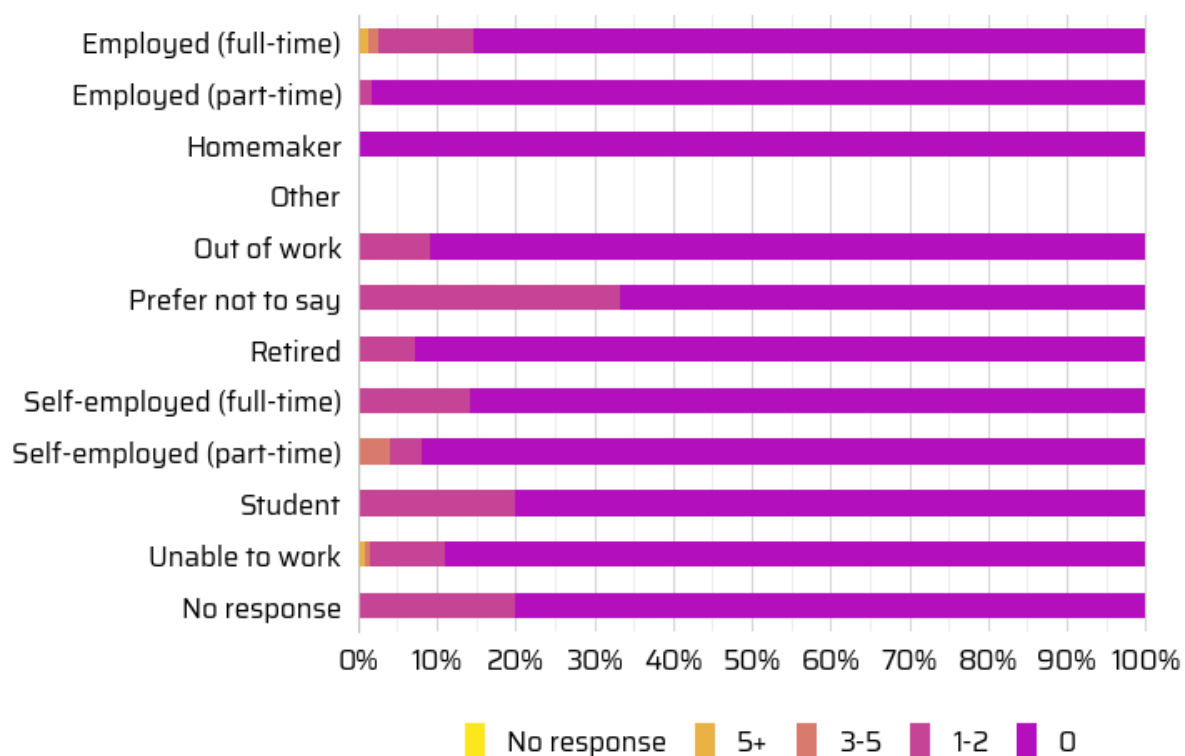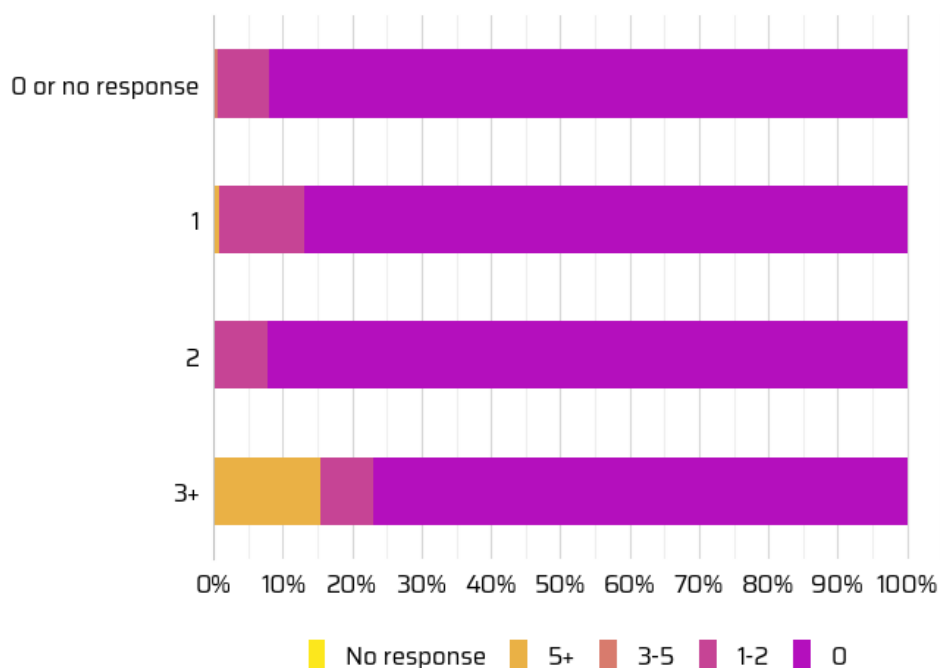


Figure 26: Frequency that NHS A&E/emergency services were sought, broken down by number of dependents.

Table 26: Frequency that NHS A&E/emergency services were sought, broken down by number of dependents.

| Number of dependents | Frequency | Respondents | Percentage |
|---|---|---|---|
| **0 or no response** | 0 | 437 | 92.0 |
| | 1-2 | 35 | 7.37 |
| | 3-5 | 3 | 0.63 |
| | 5+ | 0 | 0.0 |

| | | | |
|---|---|---|---|
| | No response | 0 | 0.0 |
| **1** | 0 | 107 | 86.99 |
| | 1-2 | 15 | 12.2 |
| | 3-5 | 0 | 0.0 |
| | 5+ | 1 | 0.81 |
| | No response | 0 | 0.0 |
| **2** | 0 | 36 | 92.31 |
| | 1-2 | 3 | 7.69 |
| | 3-5 | 0 | 0.0 |
| | 5+ | 0 | 0.0 |
| | No response | 0 | 0.0 |
| **3+** | 0 | 10 | 76.92 |
| | 1-2 | 1 | 7.69 |
| | 3-5 | 0 | 0.0 |
| | 5+ | 2 | 15.38 |
| | No response | 0 | 0.0 |

# Overall experience of healthcare
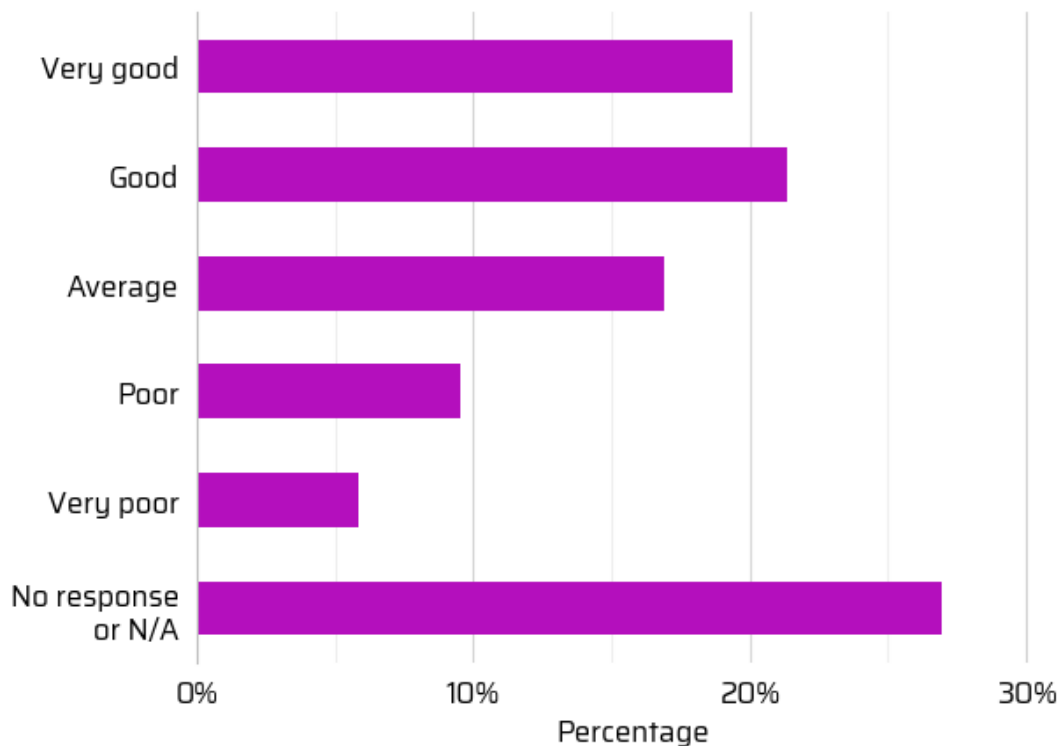


Figure 27: Overall experience of healthcare.

Table 27: Overall experience of healthcare.

| Experience | Respondents | Percentage |
|---|---|---|
| **Very good** | 126 | 19.38 |
| **Good** | 139 | 21.38 |
| **Average** | 110 | 16.92 |
| **Poor** | 62 | 9.54 |
| **Very poor** | 38 | 5.85 |
| **No response or N/A** | 175 | 26.92 |

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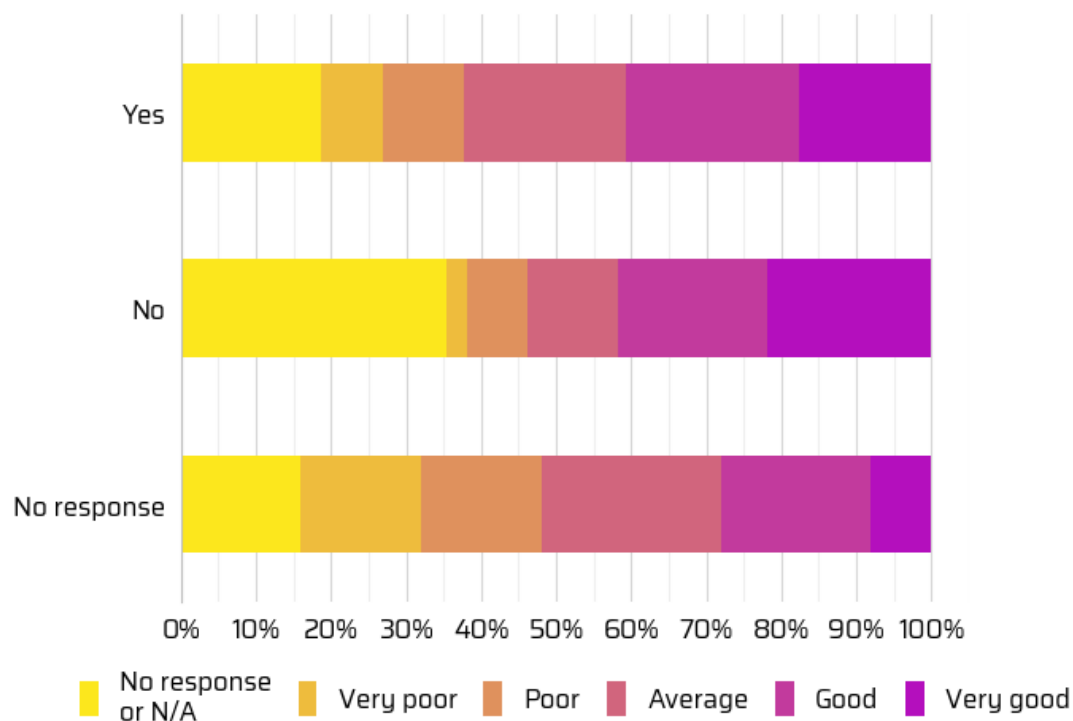


Figure 28: Overall experience of healthcare, broken down by whether diagnosed with multiple neurological conditions.

Table 28: Overall experience of healthcare, broken down by whether diagnosed with multiple neurological conditions.

| Multiple neurological conditions | Experience | Respondents | Percentage |
|---|---|---|---|
| | Very good | 53 | 17.67 |
| | Good | 69 | 23.0 |
| | Average | 65 | 21.67 |
| Yes | Poor | 32 | 10.67 |
| | Very poor | 25 | 8.33 |
| | No response or N/A | 56 | 18.67 |
| No | Very good | 71 | 21.85 |

|  |  |  |  |
|---|---|---|---|
|  | Good | 65 | 20.0 |
|  | Average | 39 | 12.0 |
|  | Poor | 26 | 8.0 |
|  | Very poor | 9 | 2.77 |
|  | No response or N/A | 115 | 35.38 |
| **No response** | Very good | 2 | 8.0 |
|  | Good | 5 | 20.0 |
|  | Average | 6 | 24.0 |
|  | Poor | 4 | 16.0 |
|  | Very poor | 4 | 16.0 |
|  | No response or N/A | 4 | 16.0 |

## Overall experience of healthcare by age group
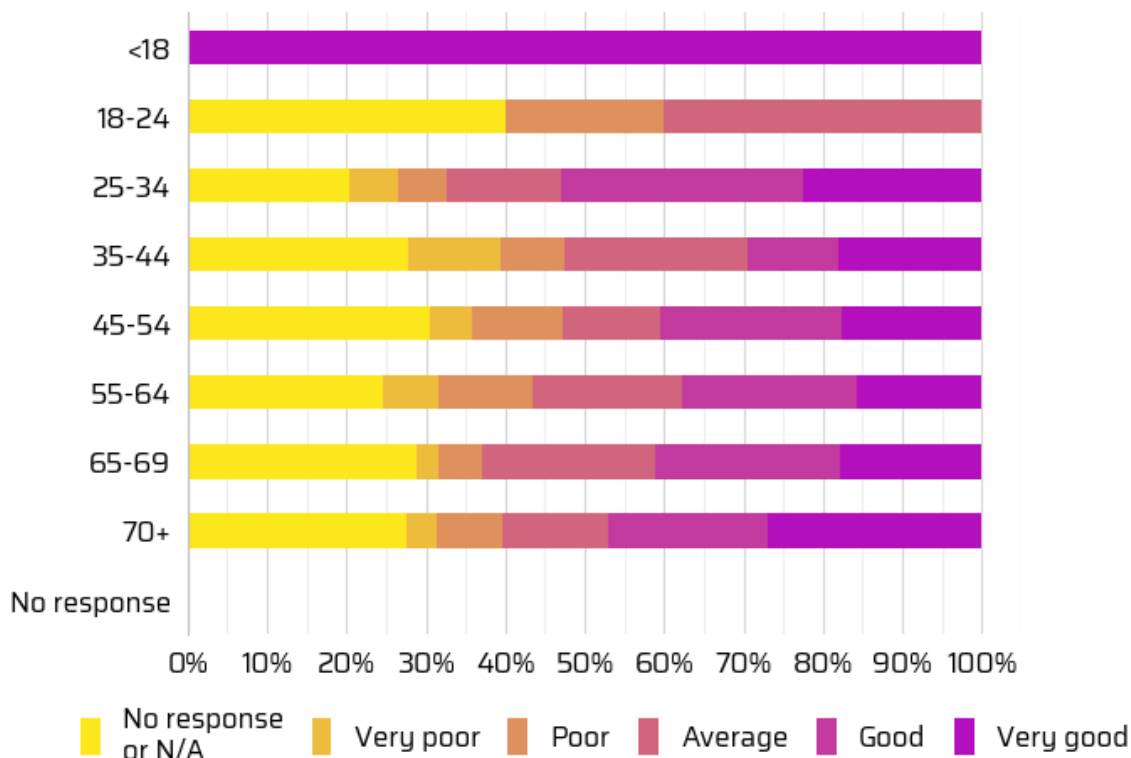


Figure 29: Overall experience of healthcare, broken down by age group.

Table 29: Overall experience of healthcare, broken down by age group.

| Age | Experience | Respondents | Percentage |
|---|---|---|---|
| | Very good | 1 | 100.0 |
| | Good | 0 | 0.0 |
| | Average | 0 | 0.0 |
| **<18** | Poor | 0 | 0.0 |
| | Very poor | 0 | 0.0 |
| | No response or N/A | 0 | 0.0 |
| | Very good | 0 | 0.0 |
| | Good | 0 | 0.0 |
| **18-24** | Average | 2 | 40.0 |
| | Poor | 1 | 20.0 |
| | Very poor | 0 | 0.0 |

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| | | | |
|---|---|---|---|
| | No response or N/A | 2 | 40.0 |
| **25-34** | Very good | 11 | 22.45 |
| | Good | 15 | 30.61 |
| | Average | 7 | 14.29 |
| | Poor | 3 | 6.12 |
| | Very poor | 3 | 6.12 |
| | No response or N/A | 10 | 20.41 |
| **35-44** | Very good | 11 | 18.03 |
| | Good | 7 | 11.48 |
| | Average | 14 | 22.95 |
| | Poor | 5 | 8.2 |
| | Very poor | 7 | 11.48 |
| | No response or N/A | 17 | 27.87 |
| **45-54** | Very good | 23 | 17.56 |
| | Good | 30 | 22.9 |
| | Average | 16 | 12.21 |
| | Poor | 15 | 11.45 |
| | Very poor | 7 | 5.34 |
| | No response or N/A | 40 | 30.53 |
| **55-64** | Very good | 31 | 15.82 |
| | Good | 43 | 21.94 |
| | Average | 37 | 18.88 |
| | Poor | 23 | 11.73 |
| | Very poor | 14 | 7.14 |
| | No response or N/A | 48 | 24.49 |
| **65-69** | Very good | 13 | 17.81 |
| | Good | 17 | 23.29 |
| | Average | 16 | 21.92 |

| | | | |
|---|---|---|---|
| | Poor | 4 | 5.48 |
| | Very poor | 2 | 2.74 |
| | No response or N/A | 21 | 28.77 |
| | Very good | 36 | 26.87 |
| | Good | 27 | 20.15 |
| **70+** | Average | 18 | 13.43 |
| | Poor | 11 | 8.21 |
| | Very poor | 5 | 3.73 |
| | No response or N/A | 37 | 27.61 |
| | Very good | 0 | 0.0 |
| | Good | 0 | 0.0 |
| **No response** | 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 gender
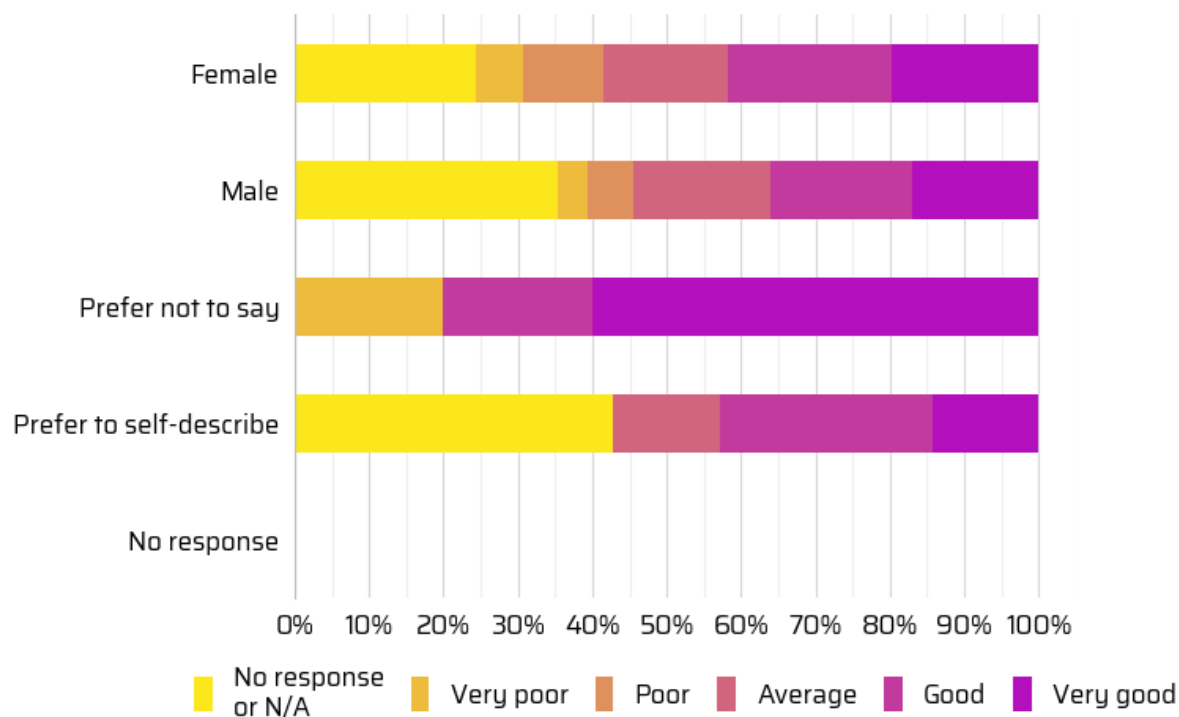


Figure 30: Overall experience of healthcare, broken down by gender.

Table 30: Overall experience of healthcare, broken down by gender.

| Gender | Experience | Respondents | Percentage |
|---|---|---|---|
| **Female** | Very good | 97 | 19.76 |
| | Good | 108 | 22.0 |
| | Average | 82 | 16.7 |
| | Poor | 53 | 10.79 |
| | Very poor | 31 | 6.31 |
| | No response or N/A | 120 | 24.44 |
| **Male** | Very good | 25 | 17.01 |
| | Good | 28 | 19.05 |
| | Average | 27 | 18.37 |
| | Poor | 9 | 6.12 |
| | Very poor | 6 | 4.08 |

| | | | |
|---|---|---|---|
| | No response or N/A | 52 | 35.37 |
| **Prefer not to say** | Very good | 3 | 60.0 |
| | Good | 1 | 20.0 |
| | Average | 0 | 0.0 |
| | Poor | 0 | 0.0 |
| | Very poor | 1 | 20.0 |
| | No response or N/A | 0 | 0.0 |
| **Prefer to self-describe** | Very good | 1 | 14.29 |
| | Good | 2 | 28.57 |
| | Average | 1 | 14.29 |
| | Poor | 0 | 0.0 |
| | Very poor | 0 | 0.0 |
| | No response or N/A | 3 | 42.86 |
| **No response** | 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
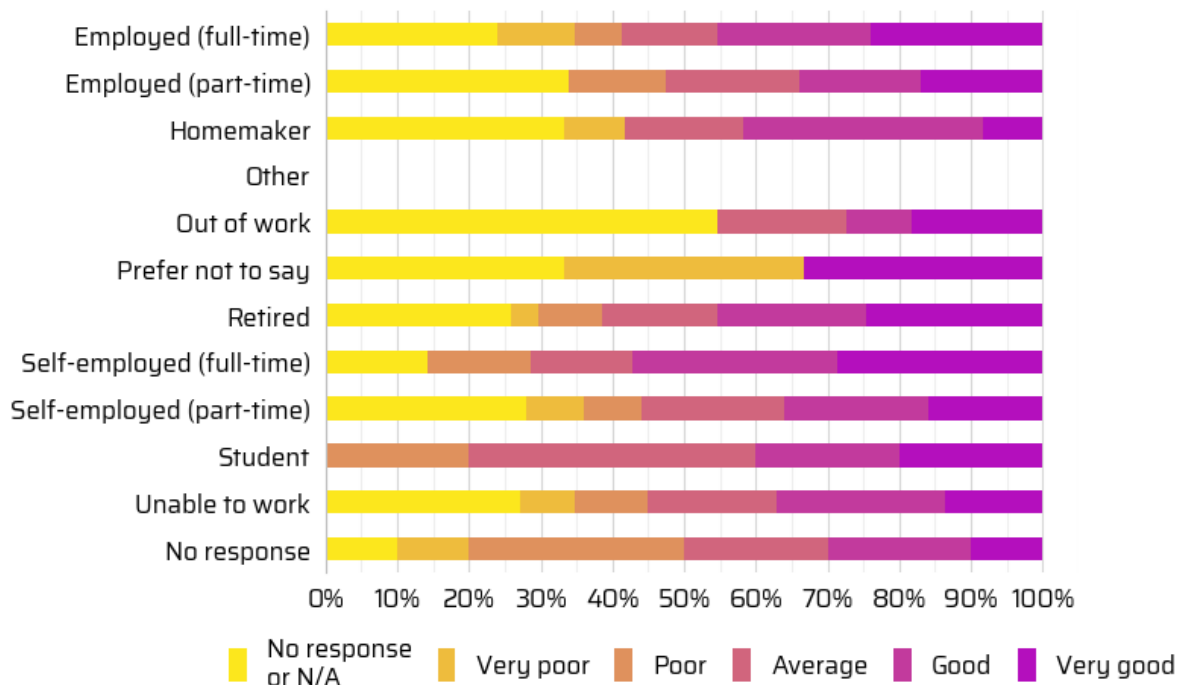


Figure 31: Overall experience of healthcare, broken down by employment status.

Table 31: Overall experience of healthcare, broken down by employment status.

| Employment status | Experience | Respondents | Percentage |
|---|---|---|---|
| | Very good | 18 | 24.0 |
| | Good | 16 | 21.33 |
| | Average | 10 | 13.33 |
| **Employed (full-time)** | Poor | 5 | 6.67 |
| | Very poor | 8 | 10.67 |
| | No response or N/A | 18 | 24.0 |
| | Very good | 10 | 16.95 |
| | Good | 10 | 16.95 |
| **Employed (part-time)** | Average | 11 | 18.64 |
| | Poor | 8 | 13.56 |
| | Very poor | 0 | 0.0 |

| | | | |
|---|---|---|---|
| | No response or N/A | 20 | 33.9 |
| **Homemaker** | Very good | 1 | 8.33 |
| | Good | 4 | 33.33 |
| | Average | 2 | 16.67 |
| | Poor | 0 | 0.0 |
| | Very poor | 1 | 8.33 |
| | No response or N/A | 4 | 33.33 |
| **Other** | 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 |
| **Out of work** | Very good | 2 | 18.18 |
| | Good | 1 | 9.09 |
| | Average | 2 | 18.18 |
| | Poor | 0 | 0.0 |
| | Very poor | 0 | 0.0 |
| | No response or N/A | 6 | 54.55 |
| **Prefer not to say** | Very good | 1 | 33.33 |
| | Good | 0 | 0.0 |
| | Average | 0 | 0.0 |
| | Poor | 0 | 0.0 |
| | Very poor | 1 | 33.33 |

| | | | |
|---|---|---|---|
| | No response or N/A | 1 | 33.33 |
| **Retired** | Very good | 58 | 24.58 |
| | Good | 49 | 20.76 |
| | Average | 38 | 16.1 |
| | Poor | 21 | 8.9 |
| | Very poor | 9 | 3.81 |
| | No response or N/A | 61 | 25.85 |
| **Self-employed (full-time)** | Very good | 2 | 28.57 |
| | Good | 2 | 28.57 |
| | Average | 1 | 14.29 |
| | Poor | 1 | 14.29 |
| | Very poor | 0 | 0.0 |
| | No response or N/A | 1 | 14.29 |
| **Self-employed (part-time)** | Very good | 4 | 16.0 |
| | Good | 5 | 20.0 |
| | Average | 5 | 20.0 |
| | Poor | 2 | 8.0 |
| | Very poor | 2 | 8.0 |
| | No response or N/A | 7 | 28.0 |
| **Student** | Very good | 1 | 20.0 |
| | Good | 1 | 20.0 |
| | Average | 2 | 40.0 |
| | Poor | 1 | 20.0 |
| | Very poor | 0 | 0.0 |

| | | | |
|---|---|---|---|
| | No response or N/A | 0 | 0.0 |
| **Unable to work** | Very good | 28 | 13.53 |
| | Good | 49 | 23.67 |
| | Average | 37 | 17.87 |
| | Poor | 21 | 10.14 |
| | Very poor | 16 | 7.73 |
| | No response or N/A | 56 | 27.05 |
| **No response** | Very good | 1 | 10.0 |
| | Good | 2 | 20.0 |
| | Average | 2 | 20.0 |
| | Poor | 3 | 30.0 |
| | Very poor | 1 | 10.0 |
| | No response or N/A | 1 | 10.0 |

# Overall experience of healthcare by number of dependents
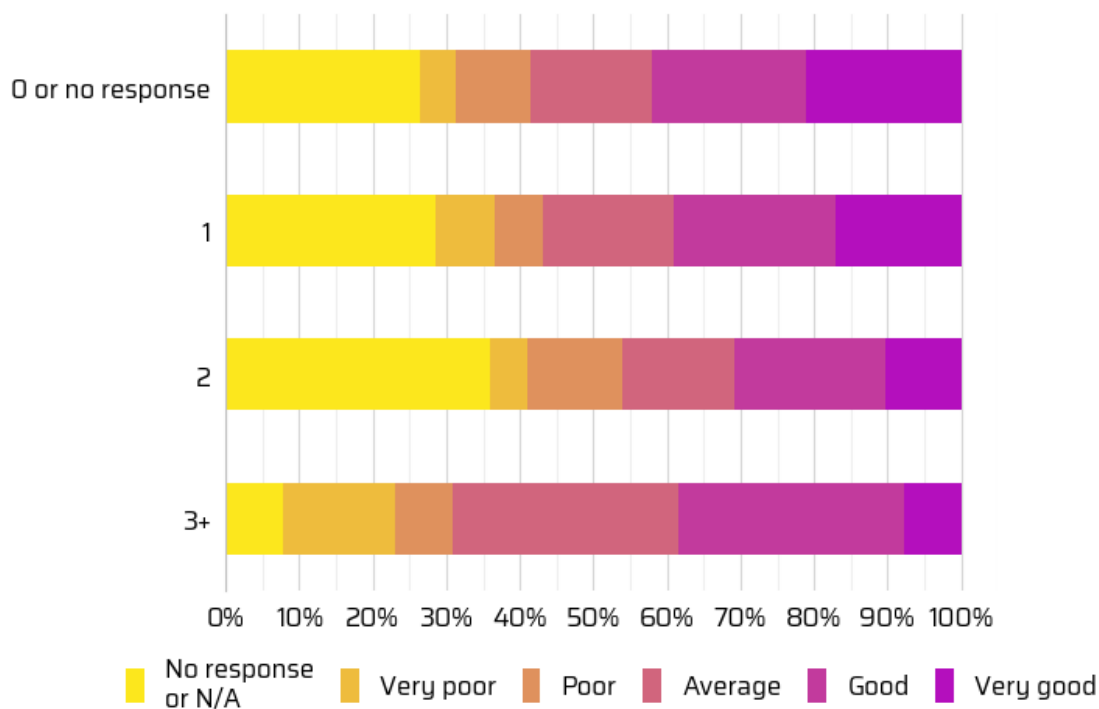


Figure 32: Overall experience of healthcare, broken down by number of dependents.

Table 32: Overall experience of healthcare, broken down by number of dependents.

| Number of dependents | Experience | Respondents | Percentage |
|---|---|---|---|
| **0 or no response** | Very good | 100 | 21.05 |
| | Good | 100 | 21.05 |
| | Average | 78 | 16.42 |
| | Poor | 48 | 10.11 |
| | Very poor | 24 | 5.05 |
| | No response or N/A | 125 | 26.32 |
| **1** | Very good | 21 | 17.07 |
| | Good | 27 | 21.95 |
| | Average | 22 | 17.89 |
| | Poor | 8 | 6.5 |

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| | | | |
|---|---|---|---|
| | Very poor | 10 | 8.13 |
| | No response or N/A | 35 | 28.46 |
| **2** | Very good | 4 | 10.26 |
| | Good | 8 | 20.51 |
| | Average | 6 | 15.38 |
| | Poor | 5 | 12.82 |
| | Very poor | 2 | 5.13 |
| | No response or N/A | 14 | 35.9 |
| **3+** | Very good | 1 | 7.69 |
| | Good | 4 | 30.77 |
| | Average | 4 | 30.77 |
| | Poor | 1 | 7.69 |
| | Very poor | 2 | 15.38 |
| | No response or N/A | 1 | 7.69 |

# Demographics

## Sample size

Total number of respondents: 650

## Diagnosis status
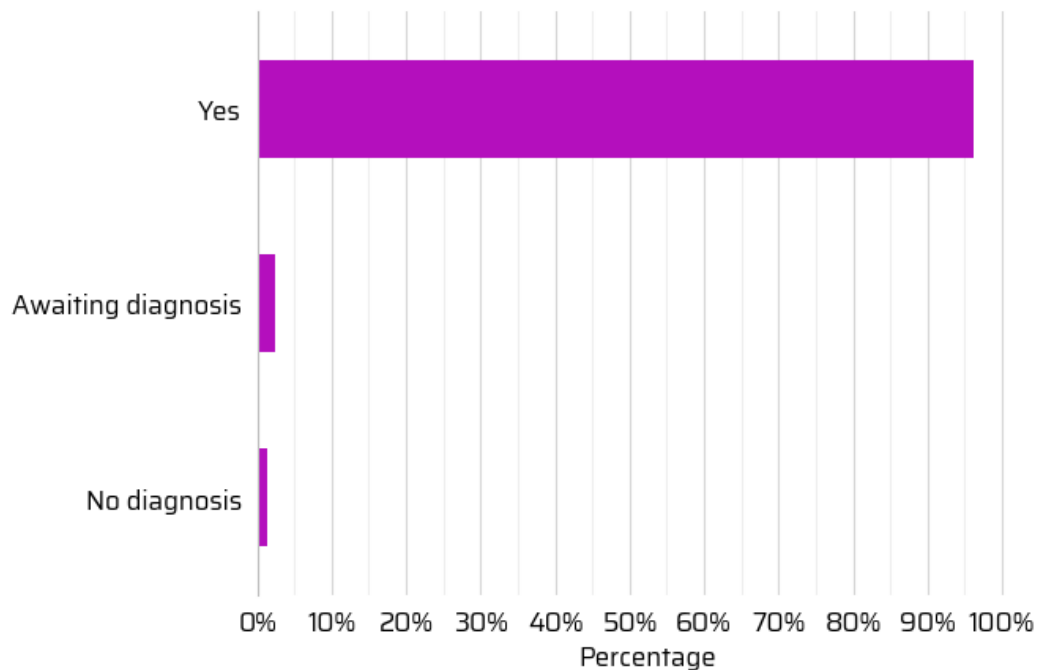


Figure 33: Diagnosis status of the respondents.

Table 33: Diagnosis status of the respondents.

| Diagnosis status | Respondents | Percentage |
|---|---|---|
| **Yes** | 625 | 96.15 |
| **Awaiting diagnosis** | 16 | 2.46 |
| **No diagnosis** | 9 | 1.38 |

## Recency of diagnosis
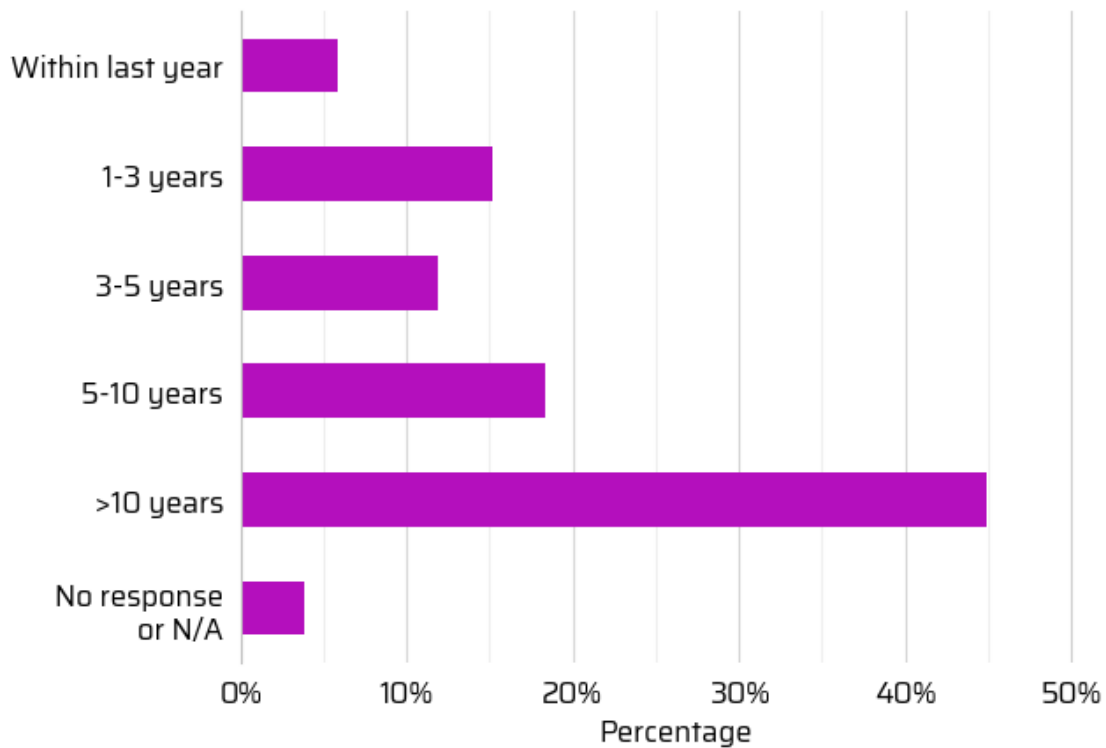


Figure 34: Recency of the respondents' first diagnosis with a neurological condition.

Table 34: Recency of the respondents' first diagnosis with a neurological condition.

| Recency | Respondents | Percentage |
| --- | --- | --- |
| **Within last year** | 38 | 5.85 |
| **1-3 years** | 99 | 15.23 |
| **3-5 years** | 77 | 11.85 |
| **5-10 years** | 119 | 18.31 |
| **>10 years** | 292 | 44.92 |
| **No response or N/A** | 25 | 3.85 |

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## Location



Figure 35: Location of the respondents.

Table 35: Location of the respondents.

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| Regions | Respondents | Percentage |
|---|---|---|
| South East | 102 | 15.69 |
| East of England | 86 | 13.23 |
| Midlands | 84 | 12.92 |
| South West | 66 | 10.15 |
| North East and Yorkshire | 63 | 9.69 |
| Scotland | 49 | 7.54 |
| London | 48 | 7.38 |
| North West | 48 | 7.38 |
| Wales | 31 | 4.77 |
| Northern Ireland | 7 | 1.08 |
| Isle of Man | 1 | 0.15 |
| No/invalid response | 103 | 15.85 |

Note: The regions in England are further divided into 'NHS England Regions'. We asked respondents for the first part of their postcodes. 37 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. 103 respondents did not provide their postcodes or offered invalid postcodes, and therefore were not included in this analysis.

## 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. 300 respondents (46.15% of the respondents that had answered this question) indicated that they have multiple neurological conditions.

| Condition | |
|---|---|
| Dystonia | |
| Multiple sclerosis | |
| Functional Neurological Disorder | |
| Fibromyalgia | |
| Epilepsy | |
| Chronic migraine | |
| Chronic fatigue syndrome | |
| Ataxia | |
| My condition(s) are not listed | |
| Migraine with aura | |
| Migraine | |
| Acquired brain injury | |
| Neuropathy | |
| Subarachnoid hemorrhage | |
| Peripheral Neuropathy | |
| Orthostatic tremor | |
| Stroke/TIA | |
| Brain or spine tumour | |
| Parkinsonism / Parkinson's | |
| Headache | |
| Hydrocephalus | |
| Chiari Malformation | |
| Cerebrospinal fluid leak | |
| Essential tremor | |
| Traumatic Brain Injury | |
| Vestibular migraine | |
| Myalgic encephalomyelitis (ME) | |
| Restless Leg Syndrome | |
| Spinal cord injury | |
| Charcot-Marie-Tooth Disease | |
| Tarlov Cysts | |
| Trigeminal neuralgia | |
| Pernicious Anaemia | |
| Arnold-Chiari syndrome | |
| Myasthenia Gravis | |
| Syringomyelia and syringobulbia | |
| Myelopathy | |
| Intacranial hypertension | |
| Cervical stenosis | |
| Complex regional pain syndrome | |
| Ehlers Danlos Syndromes | |
| Arteriovenous Malformation | |
| Tremor | |
| Post-polio syndrome | |
| Transverse myelitis | |
| Cluster headache | |
| Nerve Injury | |
| Dyslexia and alexia | |
| Dystonic tremor | |
| ADHD | |
| Cauda Equina Syndrome | |
| Functional tremor | |
| Motor neurone disease | |
| Long COVID | |
| Muscular dystrophy | |
| Meningitis | |
| Mal de Debarquement Syndrome | |
| Hemiplegic migraine | |
| Chronic Inflammatory Demyelinating Polyneuropathy | |
| Spondylosis | |
| Hereditary Spastic Paralegia | |
| Dementia | |
| Radiculopathy | |
| Disorders of vagus nerve | |
| Dysphasia and aphasia | |
| Guillain-Barre syndrome | |
| Bell's palsy | |
| Menstrual migraine | |
| Acute poliomyelitis | |
| Clonic hemifacial spasm | |
| Schwanomatosis | |
| Short Fibre Neuropathy | |
| Superficial Siderosis | |
| Cerebral Palsy | |
| Cerebral Aneurysms (Ruptured/Unruptured) | |

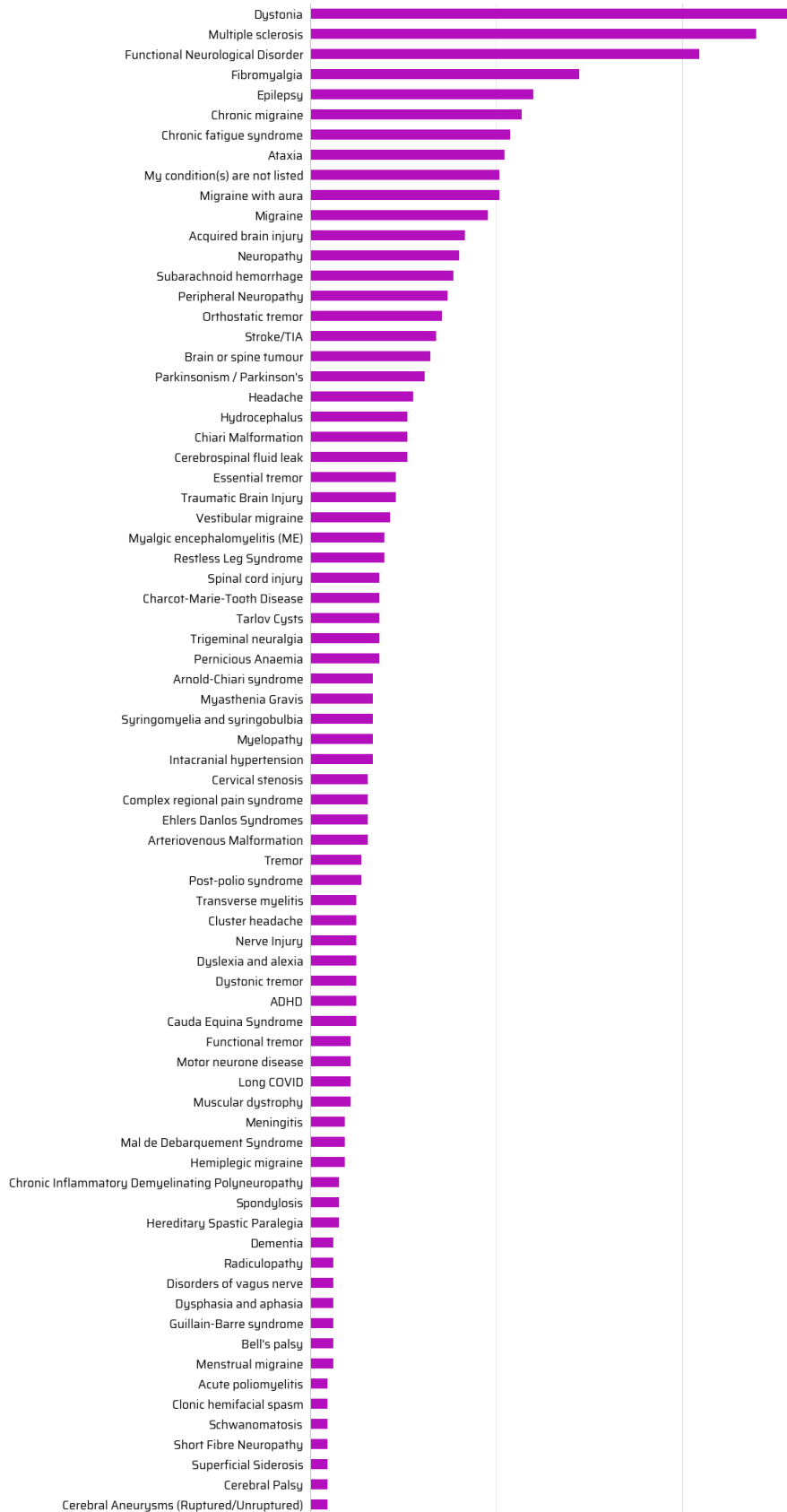The Brain & Spine Foundation registered charity no. 1098528

Figure 36: Respondents had been diagnosed with the following neurological condition(s).

Table 36: Respondents had been diagnosed with the following neurological condition(s)..

| Condition | Respondents | Percentage |
|---|---|---|
| **Dystonia** | 84 | 12.92 |
| **Multiple sclerosis** | 78 | 12.0 |
| **Functional Neurological Disorder** | 68 | 10.46 |
| **Fibromyalgia** | 47 | 7.23 |
| **Epilepsy** | 39 | 6.0 |
| **Chronic migraine** | 37 | 5.69 |
| **Chronic fatigue syndrome** | 35 | 5.38 |
| **Ataxia** | 34 | 5.23 |
| **My condition(s) are not listed** | 33 | 5.08 |
| **Migraine with aura** | 33 | 5.08 |

| | | |
|---|---|---|
| **Migraine** | 31 | 4.77 |
| **Acquired brain injury** | 27 | 4.15 |
| **Neuropathy** | 26 | 4.0 |
| **Subarachnoid hemorrhage** | 25 | 3.85 |
| **Peripheral Neuropathy** | 24 | 3.69 |
| **Orthostatic tremor** | 23 | 3.54 |
| **Stroke/TIA** | 22 | 3.38 |
| **Brain or spine tumour** | 21 | 3.23 |
| **Parkinsonism / Parkinson's** | 20 | 3.08 |
| **Headache** | 18 | 2.77 |
| **Hydrocephalus** | 17 | 2.62 |
| **Chiari Malformation** | 17 | 2.62 |
| **Cerebrospinal fluid leak** | 17 | 2.62 |
| **Essential tremor** | 15 | 2.31 |
| **Traumatic Brain Injury** | 15 | 2.31 |
| **Vestibular migraine** | 14 | 2.15 |
| **Restless Leg Syndrome** | 13 | 2.0 |
| **Myalgic encephalomyelitis (ME)** | 13 | 2.0 |
| **Spinal cord injury** | 12 | 1.85 |
| **Charcot-Marie-Tooth Disease** | 12 | 1.85 |
| **Tarlov Cysts** | 12 | 1.85 |
| **Trigeminal neuralgia** | 12 | 1.85 |
| **Pernicious Anaemia** | 12 | 1.85 |
| **Arnold-Chiari syndrome** | 11 | 1.69 |
| **Myasthenia Gravis** | 11 | 1.69 |
| **Syringomyelia and syringobulbia** | 11 | 1.69 |
| **Myelopathy** | 11 | 1.69 |

| | | |
|---|---|---|
| **Intacranial hypertension** | 11 | 1.69 |
| **Arteriovenous Malformation** | 10 | 1.54 |
| **Ehlers Danlos Syndromes** | 10 | 1.54 |
| **Cervical stenosis** | 10 | 1.54 |
| **Complex regional pain syndrome** | 10 | 1.54 |
| **Tremor** | 9 | 1.38 |
| **Post-polio syndrome** | 9 | 1.38 |
| **Transverse myelitis** | 8 | 1.23 |
| **Cluster headache** | 8 | 1.23 |
| **Nerve Injury** | 8 | 1.23 |
| **Dyslexia and alexia** | 8 | 1.23 |
| **Dystonic tremor** | 8 | 1.23 |
| **ADHD** | 8 | 1.23 |
| **Cauda Equina Syndrome** | 8 | 1.23 |
| **Functional tremor** | 7 | 1.08 |
| **Long COVID** | 7 | 1.08 |
| **Motor neurone disease** | 7 | 1.08 |
| **Muscular dystrophy** | 7 | 1.08 |
| **Hemiplegic migraine** | 6 | 0.92 |
| **Meningitis** | 6 | 0.92 |
| **Mal de Debarquement Syndrome** | 6 | 0.92 |
| **Chronic Inflammatory Demyelinating Polyneuropathy** | 5 | 0.77 |
| **Spondylosis** | 5 | 0.77 |
| **Hereditary Spastic Paralegia** | 5 | 0.77 |
| **Radiculopathy** | 4 | 0.62 |

| | | |
|---|---|---|
| **Disorders of vagus nerve** | 4 | 0.62 |
| **Dysphasia and aphasia** | 4 | 0.62 |
| **Dementia** | 4 | 0.62 |
| **Guillain-Barre syndrome** | 4 | 0.62 |
| **Bell's palsy** | 4 | 0.62 |
| **Menstrual migraine** | 4 | 0.62 |
| **Brown-Séquard syndrome** | 3 | 0.46 |
| **Dysexecutive Syndrome** | 3 | 0.46 |
| **Migraine without aura** | 3 | 0.46 |
| **Abdominal migraine** | 3 | 0.46 |
| **Multiple system atrophy** | 3 | 0.46 |
| **Encephalitis** | 3 | 0.46 |
| **Cerebral Palsy** | 3 | 0.46 |
| **Cerebral Aneurysms (Ruptured/Unruptured)** | 3 | 0.46 |
| **Short Fibre Neuropathy** | 3 | 0.46 |
| **Clonic hemifacial spasm** | 3 | 0.46 |
| **Schwanomatosis** | 3 | 0.46 |
| **Acute poliomyelitis** | 3 | 0.46 |
| **Superficial Siderosis** | 3 | 0.46 |
| **Hemicrania continua** | 2 | 0.31 |
| **Tethered Cord** | 2 | 0.31 |
| **Demyelinating disease** | 2 | 0.31 |
| **Rare and other neurological diseases** | 2 | 0.31 |
| **Spina Bifida** | 2 | 0.31 |
| **Paraplegia and tetraplegia** | 2 | 0.31 |
| **Papilloedema** | 2 | 0.31 |
| **Huntington's disease** | 2 | 0.31 |

| | | |
|---|---|---|
| **Nerve palsy** | 2 | 0.31 |
| **Tourette Syndrome** | 1 | 0.15 |
| **Disorders of other specified cranial nerves** | 1 | 0.15 |
| **Neuromyelitis optica** | 1 | 0.15 |
| **Cerebellar tremor** | 1 | 0.15 |
| **Neurofibromatosis** | 1 | 0.15 |
| **Eaton-Lambert syndrome** | 1 | 0.15 |
| **Extradural and subdural abscess** | 1 | 0.15 |
| **Epidemic vertigo** | 1 | 0.15 |
| **Medication overuse headache** | 1 | 0.15 |
| **Neurosarcoidosis** | 1 | 0.15 |
| **Cyclical vomiting syndrome** | 1 | 0.15 |
| **Myositis** | 1 | 0.15 |
| **Hemiplegia** | 1 | 0.15 |
| **Hydromyelia** | 1 | 0.15 |
| **Myopathy** | 1 | 0.15 |
| **Fatal Familial Insomnia syndrome** | 1 | 0.15 |
| **Intracranial and intraspinal abscess and granuloma in diseases classified elsewhere** | 1 | 0.15 |
| **Disorder of visual pathways** | 1 | 0.15 |
| **Myotonic disorders** | 1 | 0.15 |
| **Extrapyramidal disorder** | 1 | 0.15 |

## 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 37: Additional neurological conditions/symptoms.

| Conditions/Symptoms | Respondents | Other phrasings described by the respondents |
|---|---|---|
| **Memory problems** | 7 | "memory loss" |
| **Anxiety** | 7 | |
| **Depression** | 6 | |
| **Fatigue** | 6 | "Post Stroke Fatigue" |
| **Sleep apnoea** | 6 | "obstructive sleep apnoea" |
| **Seizures** | 5 | "focal motor seizures", "functional seizures", "Post stroke seizures" |
| **Intracranial hypotension** | 5 | "Spontaneous Intracranial Hypotension" |
| **Neuropathy** | 5 | "sensorimotor axonal neuropathy", "peripheral neuropathy", "Autonomic Neuropathy", "Small fibre neuropathy" |
| **Brain fog** | 4 | |
| **Tremor** | 4 | "functional tremor" |
| **Autism** | 4 | |
| **Functional cognitive disorder** | 3 | |
| **Radiculopathy** | 3 | |
| **Spasms** | 3 | |
| **Tinnitus** | 3 | |
| **Speech problems** | 3 | |
| **Vision problems** | 3 | |
| **Paralysis** | 3 | "Global paralysis", "Todd's paralysis" |

| | | |
|---|---|---|
| **Stenosis** | 3 | "lumber stenosis", "spinal stenosis" |
| **Numbness** | 3 | |

## Symptoms without diagnosis

Table 38: Some of the most common symptoms experienced by respondents awaiting diagnosis.

| Response | Number | Other phrasing |
|---|---|---|
| **Headache** | 6 | "orthostatic headache", "head pain" |
| **Dizziness** | 5 | |
| **Tingling and numbness** | 4 | |
| **Migraine** | 3 | |
| **Nausea** | 3 | |
| **Fatigue** | 3 | |
| **Balance problems** | 3 | "loss of balance" |
| **Cervical stenosis** | 3 | |
| **Lumber stenosis** | 3 | |

## Multiple neurological conditions
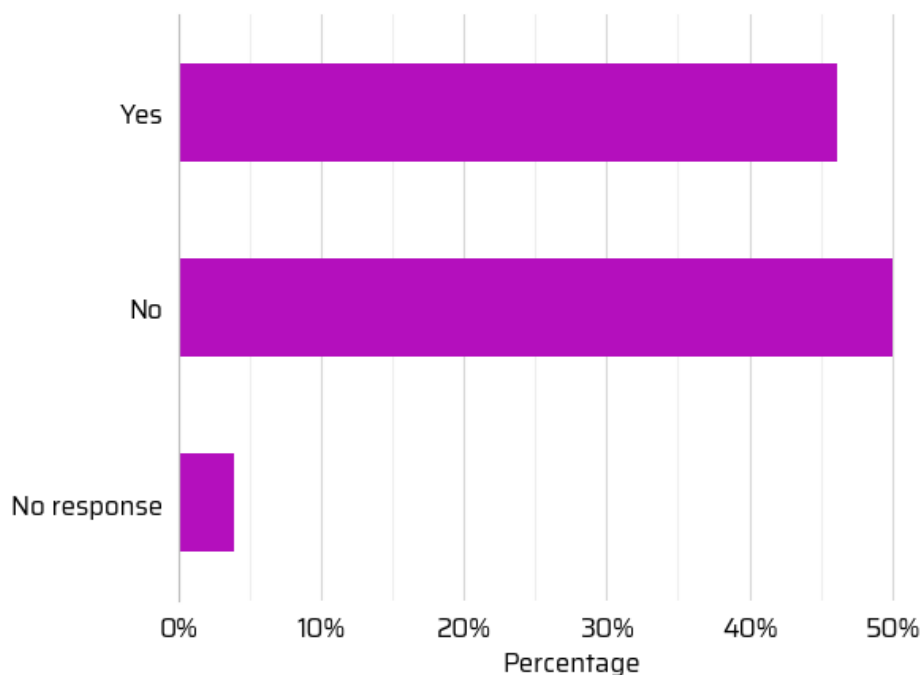


Figure 37: Whether respondents were diagnosed with multiple neurological conditions.

Table 39: Whether respondents were diagnosed with multiple neurological conditions

| Multiple neurological conditions | Respondents | Percentage |
|---|---|---|
| **Yes** | 300 | 46.15 |
| **No** | 325 | 50.0 |
| **No response** | 25 | 3.85 |

# Number of non-neurological co-occurring conditions
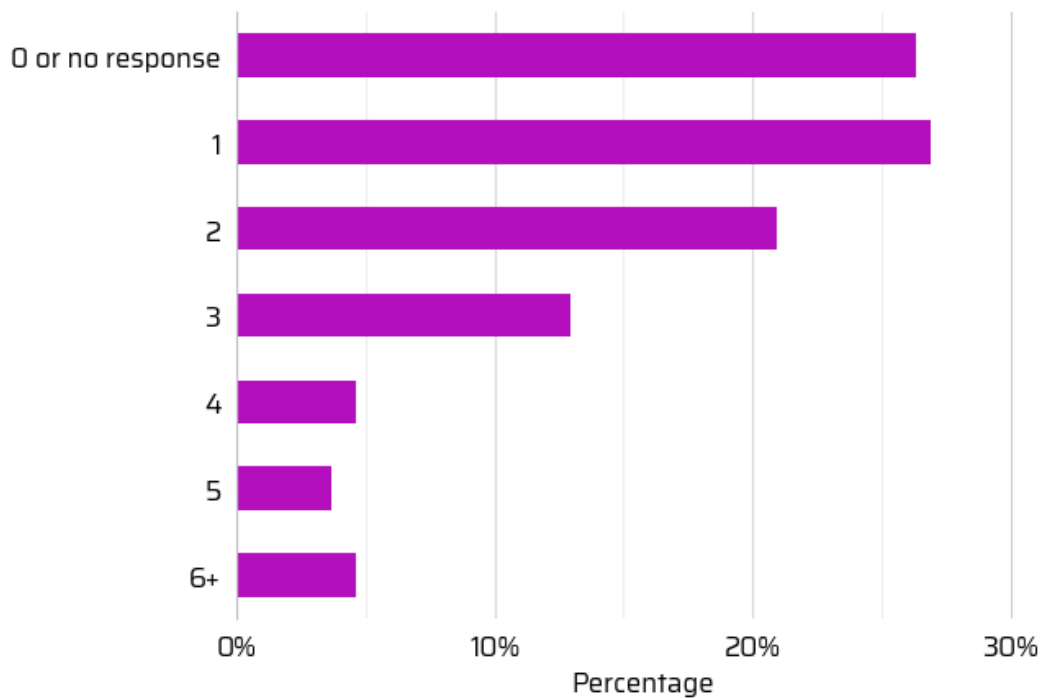


Figure 38: Number of non-neurological conditions that respondents were diagnosed with that co-occur with their neurological condition(s).

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 or no response** | 171 | 26.31 |
| **1** | 175 | 26.92 |
| **2** | 136 | 20.92 |
| **3** | 84 | 12.92 |
| **4** | 30 | 4.62 |
| **5** | 24 | 3.69 |
| **6+** | 30 | 4.62 |

## Gender
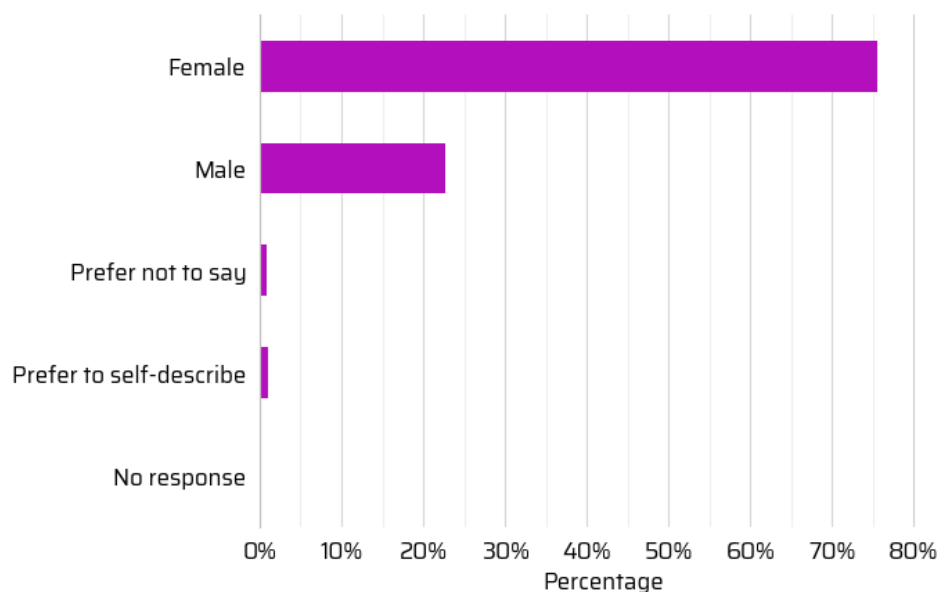


Figure 39: Gender of respondents.

Table 41: Gender of respondents.

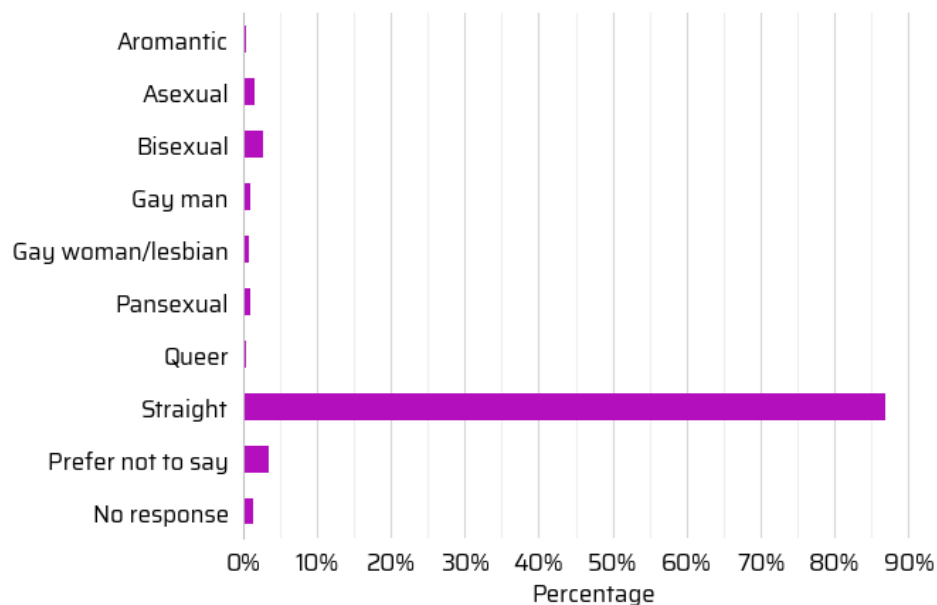| Gender | Respondents | Percentage |
|---|---|---|
| **Female** | 491 | 75.54 |
| **Male** | 147 | 22.62 |
| **Prefer not to say** | 5 | 0.77 |
| **Prefer to self-describe** | 7 | 1.08 |
| **No response** | 0 | 0.0 |

## Sexual orientation



Figure 40: Sexual orientation of respondents.

Table 42: Sexual orientation of respondents.

| Sexual orientation | Respondents | Percentage |
|---|---|---|
| Aromantic | 3 | 0.46 |
| Asexual | 10 | 1.54 |
| Bisexual | 18 | 2.77 |
| Gay man | 7 | 1.08 |
| Gay woman/lesbian | 6 | 0.92 |
| Pansexual | 7 | 1.08 |
| Queer | 3 | 0.46 |
| Straight | 564 | 86.77 |
| Prefer not to say | 23 | 3.54 |
| No response | 9 | 1.38 |

## Age
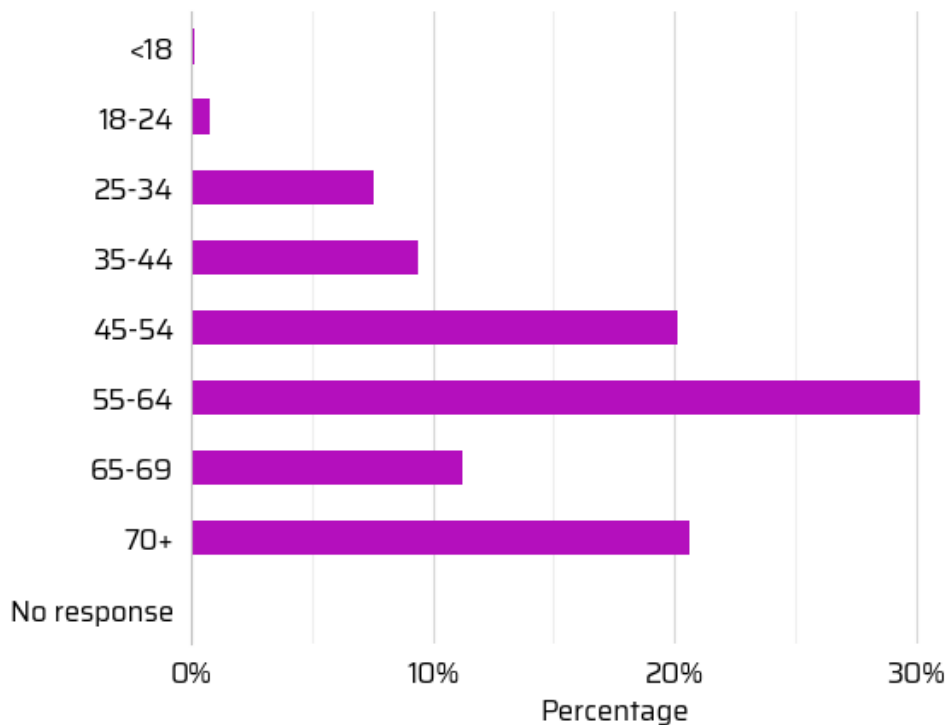


Figure 41: Age of respondents.

Table 43 Age of respondents.

| Age | Respondents | Percentage |
|---|---|---|
| **<18** | 1 | 0.15 |
| **18-24** | 5 | 0.77 |
| **25-34** | 49 | 7.54 |
| **35-44** | 61 | 9.38 |
| **45-54** | 131 | 20.15 |
| **55-64** | 196 | 30.15 |
| **65-69** | 73 | 11.23 |
| **70+** | 134 | 20.62 |
| **No response** | 0 | 0.0 |

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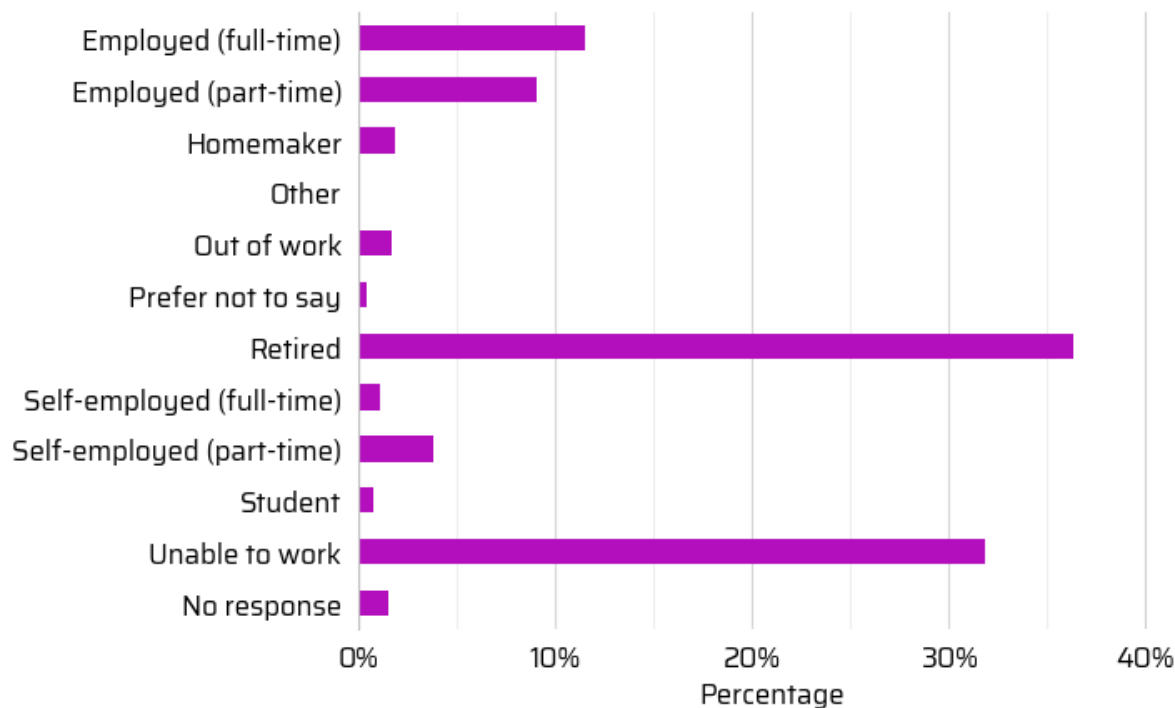
## Employment status



Figure 42: Employment status of respondents.

Table 44: Employment status of respondents.

| Employment status | Respondents | Percentage |
| --- | --- | --- |
| **Employed (full-time)** | 75 | 11.54 |
| **Employed (part-time)** | 59 | 9.08 |
| **Homemaker** | 12 | 1.85 |
| **Other** | 0 | 0.0 |
| **Out of work** | 11 | 1.69 |
| **Prefer not to say** | 3 | 0.46 |
| **Retired** | 236 | 36.31 |
| **Self-employed (full-time)** | 7 | 1.08 |
| **Self-employed (part-time)** | 25 | 3.85 |
| **Student** | 5 | 0.77 |

| | | |
|---|---|---|
| **Unable to work** | 207 | 31.85 |
| **No response** | 10 | 1.54 |

## Ethnic group
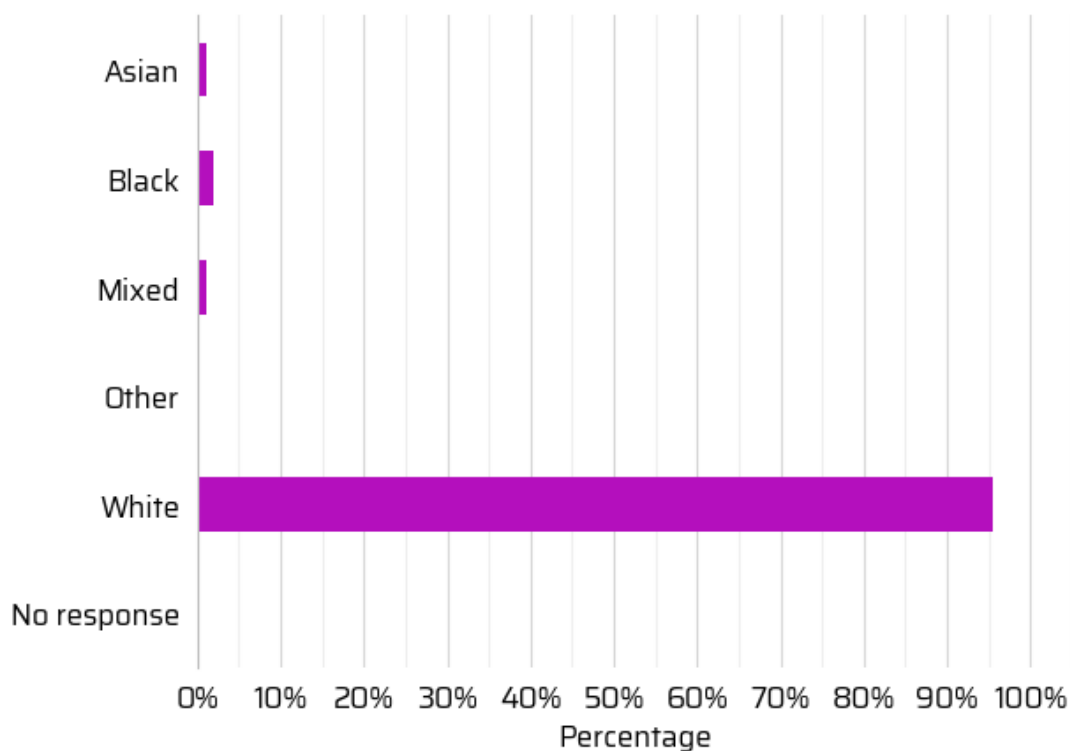


Figure 43: Ethnic group of respondents:

Table 45: Ethnic group of respondents:

| Ethnic group | Respondents | Percentage |
|---|---|---|
| **Asian** | 7 | 1.08 |
| **Black** | 13 | 2.0 |
| **Mixed** | 7 | 1.08 |
| **Other** | 2 | 0.31 |
| **White** | 621 | 95.54 |
| **No response** | 0 | 0.0 |

## Number of dependents
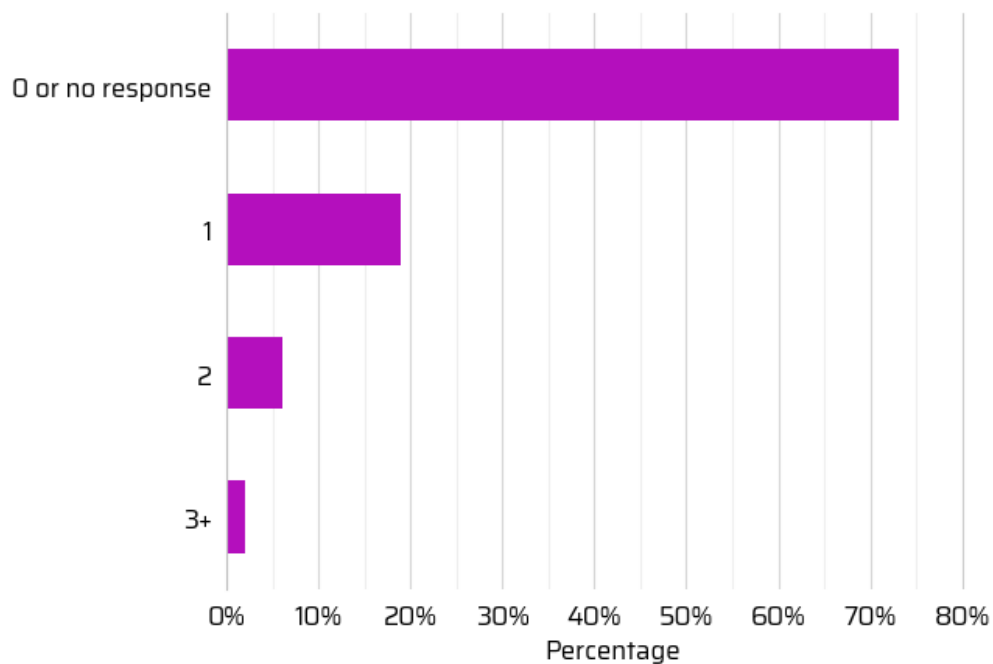


Figure 44: Number of dependents of respondents.

Table 46: Number of dependents of respondents.

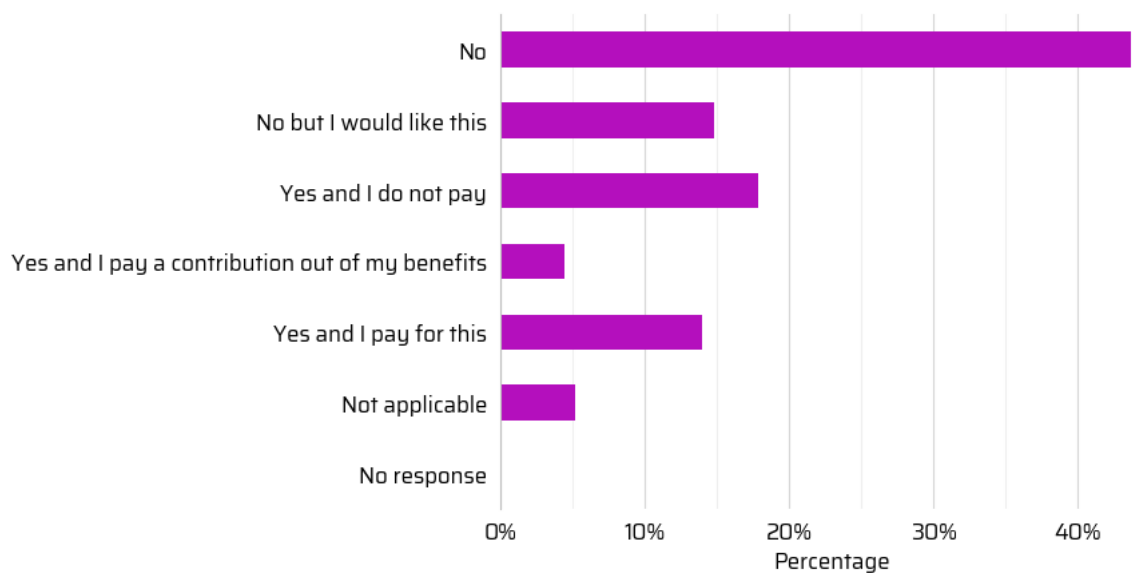| Number of dependents | Respondents | Percentage |
| --- | --- | --- |
| **0 or no response** | 475 | 73.08 |
| **1** | 123 | 18.92 |
| **2** | 39 | 6.0 |
| **3+** | 13 | 2.0 |

## Receiving care or support



Figure 45 Whether respondents receiving care or support

Table 47 Whether respondents receiving care or support

| Receive care/support | Respondents | Percentage |
|---|---|---|
| **No** | 284 | 43.69 |
| **No but I would like this** | 96 | 14.77 |
| **Yes and I do not pay** | 116 | 17.85 |
| **Yes and I pay a contribution out of my benefits** | 29 | 4.46 |
| **Yes and I pay for this** | 91 | 14.0 |
| **Not applicable** | 34 | 5.23 |
| **No response** | 0 | 0.0 |

## Appendix A – Survey Questions

| Question | Response options | | |
|---|---|---|---|
| Are you filling in this questionnaire for yourself? | Yes | No | |
| **About your condition(s)**<br><br>The next few questions are about your neurological condition(s). By sharing your condition(s) and symptoms with us, we can identify variation in care and support. You cannot be identified through the information that you share. | | | |
| **Have you been diagnosed with a neurological condition(s) or symptom(s)?**<br>Please note:<br>Awaiting diagnosis = waiting for the results of a test or a meeting with a specialist to confirm diagnosis.<br>No diagnosis = no medical advice has been sort or a possible diagnosis has not been identified yet. | Yes | Awaiting diagnosis | No diagnosis |
| **As you are either awaiting a diagnosis or do not have one, please share with us the symptoms that you are experiencing.**<br>Where possible please list or summarise your symptoms as much as you can. | Free text | | |
| **How long has it been since you were diagnosed with your primary neurological condition?**<br>If you have multiple conditions the primary condition is the one you feel has the greatest impact on your life. | Within the last year / 1-3 years / 3-5 years<br>5-10 years / Greater than 10 years | | |
| **Please tell us which neurological condition you were first diagnosed with.**<br>Please note if your condition(s) are not listed in the drop down below, there is an opportunity to share them in a subsequent question. If so, please select 'My condition(s) are not listed'. | 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?**<br><br>Please select 'No' if your condition(s) or symptoms was not listed in the previous question. | Yes | No |
| **Please tell us a second neurological condition and/or symptom you have.**<br><br>Please note if your condition(s) are not listed in the drop down below, there is an opportunity to share them in a subsequent question. If so, please select 'My condition(s) are not listed'. | 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?**<br><br>Please select 'No' if your condition(s) or symptoms was not listed in the previous question. | Yes | No |
| **Please tell us a third neurological condition and/or symptom you have.**<br><br>Please note if your condition(s) are not listed in the drop down below, there is an opportunity to share them in a subsequent question. If so, please select 'My condition(s) are not listed'. | 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?**<br><br>Please select 'No' if your condition(s) or symptoms was not listed in the previous question. | Yes | No |
| **Please tell us a fourth neurological condition and/or symptom you have.**<br><br>Please note if your condition(s) are not listed in the drop down below, there is an opportunity to share them in a subsequent question. If so, please select 'My condition(s) are not listed'. | 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?**<br><br>Please select 'No' if your condition(s) or symptoms was not listed in the previous question. | Yes | No |
| **Please tell us a fifth neurological condition and/or symptom you have.**<br><br>Please note if your condition(s) are not listed in the drop down below, there is an opportunity to share them in a subsequent question. If so, please select 'My condition(s) are not listed'. | 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?**<br><br>Please select 'No' if your condition(s) or symptoms was not listed in the previous question. | Yes | No |
| **Please tell us a sixth neurological condition and/or symptom you have.**<br><br>Please note if your condition(s) are not listed in the drop down below, there is an opportunity to share them in a subsequent question. If so, please select 'My condition(s) are not listed'. | See Appendix B for a list of conditions and symptoms | |
| **Are there any other neurological conditions or symptoms not listed under the previous question(s) that you would like to make us aware of?** | Yes | No |
| **Please list below any neurological conditions or symptoms that you experience that are not listed in the prior questions.**<br><br>We ask this as it is essential that you feel that NeuroLifeNow accurately represents you and the community of people affected by neurological conditions.<br><br>Any conditions and symptoms shared here will be considered for inclusion in future surveys. | Free text | |

| **Do you live with conditions other than your neurological condition(s)? If so, how many:**<br><br>This means any other long-term condition which is not neurological. It might include conditions related to your mental health, heart, lungs or joints. | None | 1 | 2 | 3 |
|---|---|---|---|---|
| | 4 | 5 | 6+ | |

# Campaigning for improvements to support for people affected by neurological conditions in the run up to the next General Election.

There will be a General Election in the UK before January 2025. We wish to hear from you about your priorities for the political parties and whoever forms the next UK Government.

| | |
|---|---|
| **Overall, what are the most important issues the next UK Government should address for people affected by neurological conditions?** | Access to specialists across a range of services (including consultants, nurses, physiotherapists and occupational therapists). |
| | Access to appropriate mental health support. |
| | Access to financial support. |
| | Access to appropriate social care. |
| | Access to diagnostic testing. |
| | Support for friends and family. |
| | Support to get into or retain employment. |
| | Improving primary care. |
| | **Other** |
| We want as many Parliamentary candidates as possible to show their support for people affected by neurological conditions. <br> **With this in mind, what support could the charity sector provide in order to support you to campaign in the run up to the General Election?** | Social media templates. |
| | Email templates. |
| | Guidance and support to speak to the local press. |
| | Key messages to use with parliamentary candidates. |
| | I don't wish to campaign for neurological conditions in the run up to the next election. |
| | **Other** |

## We would now like to understand what actions you might take to encourage candidates and the next UK Government to listen to people affected by neurological conditions.

Please indicate your level of confidence for each of the following campaign actions in the run-up to the next UK General Election:

| **Asking Parliamentary candidates, a question at a local event.** | 0 | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|---|

| | | | | | |
|---|---|---|---|---|---|
| **Writing to your local candidates by post.** | 0 | 1 | 2 | 3 | 4 | 5 |
| **Writing to your candidates by email.** | 0 | 1 | 2 | 3 | 4 | 5 |
| **Speaking to the local press.** | 0 | 1 | 2 | 3 | 4 | 5 |
| **Taking part in a stunt or protest.** | 0 | 1 | 2 | 3 | 4 | 5 |

## About your recent experiences of treatment and support

We would like you to rate the quality of care and support services that you have used recently. This includes specialist NHS care, emergency care (e.g. via A&E), social care or support from your GP.

These questions are asked in every survey to help us monitor changes over time.

| | | | |
|---|---|---|---|
| **Have you accessed health or care (from the NHS, a care provider and/or privately) in the past eight weeks?** | Yes | No | |
| **Overall, how would you describe your experience of health or care in the last eight weeks?** | Very Good | Good | Average |
| | Poor | Very Poor | N/A |
| **How many times have you sought A&E/emergency support from the NHS as a result of your neurological condition in the last eight weeks?** | None | | |
| | 1-2 times | | |
| | 3-5 times | | |
| | 5 or more times | | |
| **Have you had any medical appointments (including remote appointments) in the last eight weeks?** | Yes | No | Don't know |
| **How many medical appointments have you had in the last eight weeks?** | 0 | 1 | 2 | 3 |
| | 4 | 5 | 6+ | |
| **Who was your first medical appointment with?** | Neurologist | | |
| | Specialist Nurse | | |
| | Physiotherapist | | |

| | |
|---|---|
| | Speech and Language Therapist |
| | Occupational Therapist |
| | Psychologist/ Psychiatrist |
| | GP |
| | Social Services |
| | Neurosurgery |
| | Diagnostics services (e.g. a radiologist, physiologist) |
| | Rehabilitation service |
| | **Other** — Free Text |
| **How was your first medical appointment delivered?** | Phone |
| | Videoconference |
| | Via text/WhatsApp |
| | Face to face |
| | **Other** — Free text |
| **How helpful was your first medical appointment?** | It was helpful |
| | It was not helpful |
| | Don't Know |
| **Who was your second medical appointment with?** | Neurologist |
| | Specialist Nurse |
| | Physiotherapist |
| | Speech and Language Therapist |
| | Occupational Therapist |
| | Psychologist/ Psychiatrist |
| | GP |

| | |
|---|---|
| | Social Services |
| | Neurosurgery |
| | Diagnostic services (e.g. a radiologist, physiologist) |
| | Rehabilitation service |
| | **Other**    Free text |
| **How was your second medical appointment delivered?** | Phone |
| | Videoconference |
| | Via text/WhatsApp |
| | Face to face |
| | **Other**    Free text |
| **How helpful was your second medical appointment?** | It was helpful |
| | It was not helpful |
| | Don't Know |
| **Who was your third medical appointment with?** | Neurologist |
| | Specialist Nurse |
| | Physiotherapist |
| | Speech and Language Therapist |
| | Occupational Therapist |
| | Psychologist/ Psychiatrist |
| | GP |
| | Social Services |
| | Neurosurgery |
| | Diagnostic services (e.g. a radiologist, physiologist) |
| | Rehabilitation service |

| | | |
|---|---|---|
| | **Other** | Free text |
| How was your third medical appointment delivered? | Phone | |
| | Videoconference | |
| | Via text/WhatsApp | |
| | Face to face | |
| | **Other** | Free text |
| How helpful was your third medical appointment? | It was helpful | |
| | It was not helpful | |
| | Don't Know | |
| Who was your fourth medical appointment with? | Neurologist | |
| | Specialist Nurse | |
| | Physiotherapist | |
| | Speech and Language Therapist | |
| | Occupational Therapist | |
| | Psychologist/ Psychiatrist | |
| | GP | |
| | Social Services | |
| | Neurosurgery | |
| | Diagnostic services (e.g. a radiologist, physiologist) | |
| | Rehabilitation service | |
| | **Other** | Free text |
| How was your fourth medical appointment delivered? | Phone | |
| | Videoconference | |
| | Via text/WhatsApp | |

| | |
|---|---|
| | Face to face |
| | **Other** \| Free text |
| **How helpful was your fourth medical appointment?** | It was helpful |
| | It was not helpful |
| | Don't Know |
| **Who was your fifth medical appointment with?** | Neurologist |
| | Specialist Nurse |
| | Physiotherapist |
| | Speech and Language Therapist |
| | Occupational Therapist |
| | Psychologist/ Psychiatrist |
| | GP |
| | Social Services |
| | Neurosurgery |
| | Diagnostic services (e.g. a radiologist, physiologist) |
| | Rehabilitation service |
| | **Other** \| Free text |
| **How was your fifth medical appointment delivered?** | Phone |
| | Videoconference |
| | Via text/WhatsApp |
| | Face to face |
| | **Other** \| Free text |
| **How helpful was your fifth medical appointment?** | It was helpful |
| | It was not helpful |

| | |
|---|---|
| | Don't Know |
| **Who was your sixth medical appointment with?** | Neurologist |
| | Specialist Nurse |
| | Physiotherapist |
| | Speech and Language Therapist |
| | Occupational Therapist |
| | Psychologist/ Psychiatrist |
| | GP |
| | Social Services |
| | Neurosurgery |
| | Diagnostic services (e.g. a radiologist, physiologist) |
| | Rehabilitation service |
| | **Other** — Free text |
| How was your sixth medical appointment delivered? | Phone |
| | Videoconference |
| | Via text/WhatsApp |
| | Face to face |
| | **Other** — Free text |
| How helpful was your sixth medical appointment? | It was helpful |
| | It was not helpful |
| | Don't Know |
| To what extent do you feel your mental wellbeing needs are being met? | To a great extent |
| | To a moderate extent |
| | To a small extent |

| | |
|---|---|
| | Not at all |
| | Don't Know |

## Quality of life and wellbeing

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

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

| | | |
|---|---|---|
| **Which of the following describes how you feel at the moment?** **Please select all that apply.** | Calm | |
| | Well supported | |
| | Anxious | |
| | Hopeless | |
| | Lonely | |
| | **Other** | Free text |
| **What other words would you use to describe how you feel at the moment?** | Free text | |
| **To what extent is your quality of life affected by your neurological condition?** | To a great extent | |
| | To a large extent | |
| | Somewhat | |
| | A little | |
| | Not at all | |

## About you

The following questions help us to identify any potential variation in the daily realities, care, and support, while also aiding us in striving to be as representative as possible.

| | |
|---|---|
| **What is your age range?** | Under 18 years of age |
| | 18 to 24 years of age |
| | 25 to 34 years of age |

| | |
|---|---|
| | 35 to 44 years of age |
| | 45 to 54 years of age |
| | 55 to 64 years of age |
| | 65 to 69 years of age |
| | Over 70 years of age |
| **To which of these ethnic groups do you belong?** | White British |
| | White Irish |
| | Any other White background |
| | White and Black Caribbean |
| | White and Asian |
| | Any other mixed background |
| | Indian |
| | Pakistani |
| | Bangladeshi |
| | Any other Asian background |
| | Caribbean |
| | African |
| | Any other Black background |
| | Chinese |
| | Any other ethnic background |
| **What is your gender?** | Male |
| | Female |
| | Prefer to self-describe |
| | Prefer not to say |

| | |
|---|---|
| **What is your sexual orientation?** | Aromantic |
| | Asexual |
| | Bisexual |
| | Gay man |
| | Gay woman/lesbian |
| | Pansexual |
| | Queer |
| | Straight (heterosexual) |
| | Prefer not to say |
| | **Other** — Free text |

| | |
|---|---|
| **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** — Free text |

| | | | | |
|---|---|---|---|---|
| **How many dependents live with you?** | 1 | 2 | 3 | 4 |
| | 5 | 6+ | | |
| | Yes and I pay for this | | | |

| | |
|---|---|
| **Do you receive any care or support at home for your day-to-day life?** | Yes and I pay a contribution out of my benefits |
| | Yes and I do not pay |
| | No but I would like this |
| | No |
| | Not applicable |

## Communicating with you.

If you are happy to hear from us about how your support is benefitting people affected by neurological conditions, please complete the following questions.

You can stop receiving communications or change any of your preferences at any time by contacting us at: info@neurolifenow.org.

For full details of what information, we hold and how we process your data, please see our privacy policy.

| | |
|---|---|
| **What is your first name?**<br><br>Your name will only be used for communications purposes.<br><br>They will not be used as part of the research or shared with third parties. | Free text |
| **What is your surname?**<br><br>Your name will only be used for communications purposes.<br><br>They will not be used as part of the research or shared with third parties. | Free text |
| **What is your Email Address?**<br><br>Your email will only be used for communications purposes.<br><br>It will not be used as part of the research or shared with third parties. | Free text |
| **What is the first line of your address?**<br><br>Your address will only be used for communications purposes. It will not be used as part of the research or shared with third parties. | Free text |
| **The first part of your postcode?**<br><br>i.e. E1, HP15, L1, EC1, etc | Free text |

| | |
|---|---|
| The first part of your post code is used in the research to identify differences in experience depending on where people live in the UK, while also allowing us to monitor if we are reaching people from all over the UK.<br><br>It is also used for communication purposes. | |
| **What is the second part of your postcode?**<br><br>The second part of your postcode will be combined with the first part and used for communications only.<br><br>It will not be used as part of the research or shared with third parties. | Free text |

## Appendix B – List of Conditions

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

| | | |
|---|---|---|
| Headache associated with exercise | Hemicrania continua | Hemicranial Corrina |
| Hemiplegia | Hemiplegic migraine | Hereditary Spastic Paralegia |
| High altitude headache | Huntington's disease | Hydrocephalus |
| Hydromyelia | Hypnic headache | Intacranial hypertension |
| Intracranial abscess and granuloma | Intracranial and intraspinal abscess and granuloma in diseases classified elsewhere | Intracranial and intraspinal phlebitis and thrombophlebitis |
| Intraspinal abscess and granuloma | Kennedy's disease | Leukoencephalitis |
| Long COVID | Mal de Debarquement Syndrome | Malaria |
| Medication overuse headache | Melkersson's syndrome | Meningeal tuberculoma |
| Meningitis | Menstrual migraine | Migraine |
| Migraine with aura | Migraine with brainstem aura | Migraine without aura |
| Motor neurone disease | Multiple sclerosis | Multiple system atrophy |
| Muscular dystrophy | Myalgic encephalomyelitis (ME) | Myasthenia Gravis |
| Mycoses | Myelopathy | Myopathy |
| Myositis | Myotonic disorders | Narcolepsy and cataplexy |
| Nerve Injury | Nerve palsy | Nerve Tumour |
| Neurofibromatosis | Neuromyelitis optica | Neuropathy |
| Neurosarcoidosis | Optic atrophy | Orthostatic tremor |
| Papilloedema | Paraplegia and tetraplegia | Parkinsonian tremor |
| Parkinsonism / Parkinson's | Peripheral Neuropathy | Pernicious Anaemia |
| Post-polio syndrome | Postzoster neuralgia | Progressive multifocal leukoencephalopathy |
| Rabies | Radiculopathy | Rare and other neurological diseases |
| Refsum's Disease | Restless Leg Syndrome | Schwanomatosis |
| Short Fibre Neuropathy | Spina Bifida | Spinal cord injury |
| Spinal muscular atrophy | Split Cord | Spondylosis |
| Stroke/TIA | Subacute sclerosing panencephalitis | Subarachnoid hemorrhage |
| Superficial Siderosis | Syringomyelia and syringobulbia | Tarlov Cysts |

| | | |
|---|---|---|
| Tension type headache | Tethered Cord | Tourette Syndrome |
| Toxic encephalopathy | Toxoplasma meningoencephalitis | Transverse myelitis |
| Traumatic Brain Injury | Tremor | Trigeminal neuralgia |
| Tuberculous meningitis | Vascular myelopathies | Vestibular migraine |
| My condition(s) are not listed | | |