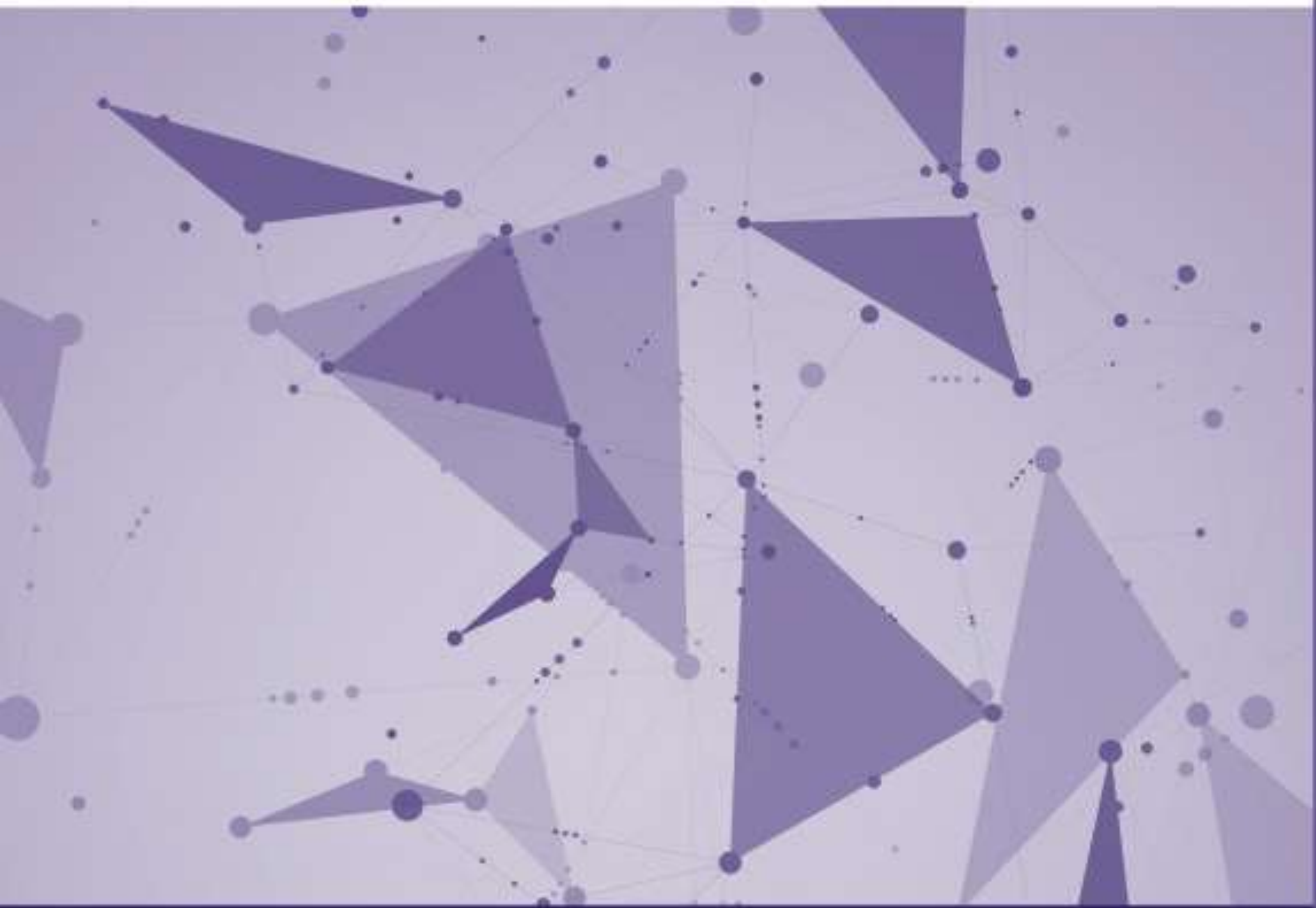
THE NEUROLOGICAL ALLIANCE

Quality Health



NEURO PATIENCE

Still waiting for improvements in treatment and care

The National Neurology Patient Experience Survey 2018/19: Technical report

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1. Introduction

The 2018/19 National Neurology Patient Experience Survey presents a comprehensive picture of the experiences of people living with a neurological condition in England. It is the only pan-neurological survey exploring the views of people across the spectrum of neurological conditions. This is the third iteration of survey, which has been run biennially by The Neurological Alliance since 2014.

Through gathering data on a wide range of topics - from diagnosis and information, to hospital care, support for mental wellbeing, access to social care, welfare and employment – the survey findings present a comprehensive picture of people's experiences of living with a neurological condition in 2018/19. In the absence of nationally collected neurological patient outcome measures, or social care data that is segregated by condition, this approach provides intelligence about how well health and care services in England are performing for people with neurological conditions.

For 2018/19, data collection for the survey was undertaken in clinics for the first time. This was in addition to an online survey, as had been used in previous years. Through developing the methodology alongside survey experts Quality Health, and in partnership with a steering group of The Neurological Alliance's member organisations, the survey received a higher number of responses than ever before. The statistics and free text responses it has produced brings the experiences of over 10,000 people with neurological conditions to the fore.

This technical report, authored by Quality Health on behalf of The Neurological Alliance, provides details of the background to the survey, the new dual methodology, and data results tables. It accompanies a policy analysis report[1], which presents a thematic discussion of the results in relation to the policy context, draws conclusions, and makes recommendations for system change accordingly.

This year the results are also broken down to regional level for the first time. The accompanying online interactive map[2] shows the patient experience survey scores for each Sustainability and Transformation Partnership footprint, revealing wide geographic variation in the experience of people with neurological conditions.

Overall, based on analysis of all the survey data, The Neurological Alliance's three key messages are that care and support for people with neurological conditions must be:

- **Accessible**; the speed of access to specialists must improve overall and should not vary depending on where you live
- **Personalised** and tailored to the needs of each individual
- **Holistic,** addressing people's mental health, social care needs, and their financial security.

The Neurological Alliance is using the data to make the case for neurology to be the focus of improvement efforts in the NHS at a regional as well as a national level. The recommendations are as follows:

- A national neurology plan for England should be urgently developed to address delays in the system and regional variation in access to services.
- The Sustainability and Transformation Partnerships/Integrated Care Systems should include neurology as a priority area for improvement in their plans.

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[1] The policy report can be found at www.neural.org.uk/resource_library/neuro-patience

[2] A link to the map is available at www.neural.org.uk/patient-experience-survey

- Person centred care should be provided for all people with neurological conditions, delivering on the NHS Long Term Plan commitment relating to personalised and coordinated care.
- All people with neurological conditions should be afforded the opportunity to live dignified, fulfilled lives, maximising their wellbeing through:
    - a resolution of the social care crisis, including a long-term funding settlement.
    - a redoubling of efforts to tackle structural and institutional barriers to employment.
    - reform of the welfare benefits system.

Neurology should be included as a priority for mental health improvement initiatives aimed at people with long term conditions, building on previous parity of esteem calls[3].

2. Background and methodology

2.1 Background

- This is the third iteration of the National Neurology Patient Experience Survey, gathering the views of people with neurological conditions across England. The survey was previously run in 2014 and 2016. For 2018/19 the methodology has been updated and renewed – gathering responses in neurology clinics as well as via an online survey.
- The Neurological Alliance engaged survey company Quality Health to undertake the survey. The Neurological Alliance and Quality Health worked in close partnership to develop and test the methodology and survey questions, as well as to analyse and report on the data.
- Data was collected between 17 October 2018 to 22 March 2019. The survey received 10,339 responses.

2.2 Objectives

The survey had five main objectives, to gather data about the experience of people with neurological conditions living in England in order to:

1. Enhance nationally collected data and intelligence about neurological services, by providing evidence about the experience of people with neurological conditions.
2. Provide the neurological community with evidence about patient experience in order to influence national policy.
3. Provide condition-specific data to members of The Neurological Alliance to inform their work.
4. Provide intelligence about the experiences of people with neurological conditions to inform The Neurological Alliance's strategic priorities and longer-term work.
5. Produce a 'state of the nation' report about people with neurological conditions and neurological services.

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[3] See The Neurological Alliance (2017) *Parity of Esteem for People Affected by Neurological Conditions*.

For 2018/19 there were three additional objectives:

6. To understand more about the experiences of people with neurological conditions who have been diagnosed in the last two years or who are still waiting for a diagnosis.
7. To achieve an even spread of responses from across England, and in large enough numbers (target 10,000), in order to analyse the data at regional sustainability and transformation partnerships (STP) level.
8. To improve the overall methodology of the survey in order to produce robust data which will stand up to external scrutiny.

2.3 Methodology

The methodology for this year's survey was a dual mode of data collection: to collect feedback from respondents via an anonymous online link (predominantly promoted via The Neurological Alliance's members), and by handing out paper copies of the questionnaire in neurological clinics across England. This method was chosen as working to collect responses in clinics would provide a far greater number of respondents diagnosed within the last two years than promotion via The Neurological Alliance's member organisations – whose communities tend to have been living with their neurological condition for longer. Doing so would also offer the possibility of increasing the overall number of responses in order to improve the reliability of the data.

A summary of the methodology is below:

- A new questionnaire was developed using the previous 2016 Neurological Alliance survey as a general guide but drew on Quality Health's extensive experience in running other national survey programmes including the National Cancer Patient Experience Survey (CPES).
- The questionnaire was developed alongside a project steering group, comprising representatives from the main neurological conditions, along with representatives covering rarer conditions.
- Cognitive testing was carried out with 14 people with neurological conditions to ensure that the final questionnaire could capture the information required in the most straightforward and effective way.
- A final questionnaire was produced in July 2018 in preparation for the first pilot. This was produced as a paper copy for use in a pilot, which took place in July 2018 in three clinics (Southampton, Poole, Oxford).
- Following a challenging first pilot, it was decided to run a second pilot with some tweaks to the methodology (in particular, it was discovered that ballot boxes were far more successful in neurological clinics than offering a freepost envelope), as well as some tweaks to the questionnaire wording.
- An extended second pilot took place from the end of October 2018 to the start of December 2018 in two key clinics (Watford and Salford). This enabled further development and refinement of the methodology.
- During this time a replica of the paper survey was produced as an online survey. Quality Health carried out User Acceptance Testing (UAT). UAT is the last phase of the software testing process. During UAT, actual software users test the software to make sure it can handle required tasks in real-world scenarios, according to specifications. In this instance, it involved several test submissions using the online tool, to check all functionality.

- The online survey was launched on 17 October 2018 and ran until 22 March 2019. The online survey was promoted to people with neurological conditions via The Neurological Alliance's member organisations and via The Neurological Alliance's own channels of communication.

- Based on a review of both pilots, and in discussion with neurologists and the project steering group, the methodology was further refined (details provided below).

- The Neurological Alliance drew up a list of neurology outpatient clinics to recruit to the full rollout, identifying at least one hospital per STP area. Neuroscience centres were prioritised, or neurology centres in their absence, due to the high volume of neurology patients seen in these clinics. Only where neither of these were present were district general hospitals (DGHs) chosen. DGHs were selected largely at random, though with some exceptions where it was known that such a low volume of patients would be seen at a particular DGH that respondent rates would likely be compromised.

- There was some clinic self-selection, as some clinics that were approached either never responded, or declined to participate. Similarly, a couple of requests were made by those engaged for their linked clinic(s) to become involved.

- The Neurological Alliance, together with Quality Health, engaged with 44 different neurological units. Most units were sent 300 paper copies of the questionnaire to hand out to patients, with a few clinics being sent more on request part way through the rollout. Smaller clinics were sent 150 paper questionnaires.

- The paper survey officially opened in clinics on 21 January 2019 and closed in line with the online survey on 22 March 2019.

- Quality assurance was carried out by Quality Health to improve, where possible, the consistency and accuracy of the data. Quality assurance included the following steps:

    - Check of the prevalence of conditions within the data versus national neurology data to ascertain if there were any gaps.

    - All condition responses contained in the 'other' field went through extensive data cleansing to ensure the accuracy of condition numbers (for primary conditions only).

2.3.1 Questionnaire design and development

The questionnaire was designed and developed between April and July 2018. This involved a detailed process of drafting, reviewing, testing and revising the questions. Quality Health worked closely with The Neurological Alliance on designing and agreeing the final question set. In addition, Quality Health worked alongside a project steering group made up of a range of The Neurological Alliance member organisations which included representatives from all major neurological conditions.

As a part of the process, cognitive testing was carried out with 14 volunteers with a range of neurological conditions; their time and input into the process is greatly appreciated. The volunteers completed the draft questionnaire and were then invited to share their answers to the questions, and to comment on the wording, the response options, any omissions; and any comments on the layout and length of the survey. After these interviews a report was provided to The Neurological Alliance and the project steering group. A number of changes were made, and a revised questionnaire was then re-tested.

Scoring

A scoring methodology was developed so that one score per question could be reported, instead of the frequencies of individual response options. This enabled easier comparison across different groups and locations. The scoring is consistent in indicating better or worse experiences: a higher score indicates a more positive response. This can be confusing on some questions, so particular attention is drawn to scores around quality of life – a lower percentage indicates that there is a more severe impact on quality of life, a higher score suggests a lower impact on quality of life. The full scoring methodology is attached to this report as Appendix A.

2.3.2 Pilot 1

As this was the first time that The Neurological Alliance survey had followed a dual send out method (both online and as a paper copy in neurology clinics), it was decided that a pilot was needed to test the methodology and develop and refine it if needed.

Three clinics were recruited to test the methodology directly with patients over a two-week period. The first pilot produced some key learnings which helped in the development of the methodology.

	Pilot 1 finding	**Change made to the methodology**
#1	Patients who are asked to complete the survey and place in a ballot box are most likely to complete the survey.	All clinics that take part to be sent ballot boxes.
#2	Patients who are given a questionnaire with a prepaid envelope and asked to complete at home are highly unlikely to ever return it.	All clinics that take part to be sent ballot boxes.
#3	Making contact with clinics in busy hospitals is extremely challenging and time consuming. Often the key contact is not available.	All clinics that take part to be asked for the names of three key contacts and these to be placed on a form in advance of the survey going live.
#4	Ensuring there is a neurologist who is fully bought into the process and champions the survey is a critical driver for success.	Attempting to ensure all clinics that take part have a neurologist to champion the survey.
#5	Promoting the survey to patients as soon as they arrive is critical to ensuring they have adequate time to complete it and hand it in.	Ensure reception staff and clinic manager is briefed to promote the survey as soon as patients arrive.
#6	Patients are concerned over the length of the survey.	Ensure clinic staff suggested to the patient that it was ‘mainly tick boxes’ and did not actually take too long in practice.
#7	Concerns over anonymity.	Briefing pack further developed and refined to include information for staff on how the survey was completely confidential and anonymous – and advice on how to reassure patients of this.
#8	Measuring ‘success’ is extremely challenging as it is hard to get an accurate picture of how well the survey is going from clinics.	This only became evident at the end of the first pilot – and became a focus for the second pilot by: • Ensuring clinic staff were asked to count questionnaires handed

		out and report the number to Quality Health; - Ensuring clinic staff counted the number of questionnaires in the ballot box; - Waiting on verified returns to Quality Health before reporting on numbers.
#9	Clinics overestimate the number of completed questionnaires – sometimes by a very high margin.	Only relying on verified data.
#10	Running a questionnaire during the summer (in this case July) is challenging.	Ensuring that full roll out is at a different time of year.
#11	Two weeks is not long enough to run an in-clinic programme (it often takes this long to set up and embed) – and therefore seriously affects response rate.	Allowing clinics more time to embed the questionnaire and run fieldwork during full roll out.
#12	Very low take up of large print version of questionnaire	Ensure large print is made available 'on request' for the full roll out and not pre-printed.

2.3.3 Pilot 2

The first pilot was invaluable in helping to develop and refine the methodology. However, it did not produce the level of response needed to validate this part of the survey. It was therefore decided to run a second pilot with the refined methodology before the survey was fully rolled out.

	Pilot 2 finding	**Change made to the methodology**
#1	Ballot boxes were more successful as tested in Pilot 1. However, some patients still attempted to take questionnaires home.	Briefing pack refined for clinics to ensure staff briefed patients that they were to hand in a completed survey before leaving.
#2	Having three key contacts ensured better communication – but this was still challenging at busy times.	Continuing to ensure the names of three contacts are collected. Ensure contact is made outside of clinic times where possible.
#3	Having a neurologist who is fully bought into the process and championed the survey (as tested in Pilot 1) – is hugely important.	Continuing to ensure all clinics that take part have a Neurologist to champion the survey. All clinics that take part to be asked for the names of three key contacts and these to be placed on a form in advance of the survey going live.
#4	Promoting the survey to patients as soon as they arrive remains critical to ensuring they have adequate time to complete it and hand it in.	Continuing to ensure reception staff and clinic manager are briefed to promote the survey as soon as patients arrive.
#5	Staff continue to over-estimate the number of completed questionnaires.	Waiting for verified numbers before reporting back to client.
#6	The longer the survey is open in-clinic, the more successful it is.	Allowing the longest possible in-clinic fieldwork time during full rollout.

Pilot 2 was significantly more successful. Following all the key learnings from both pilots, it was clearly demonstrated that this was a viable survey to run in neurology clinics during full roll out. It was therefore decided to proceed with full roll out in neurology clinics in January 2019 using the refined methodology was used.

2.3.4 Sampling and data

The online survey was promoted via The Neurological Alliance's member organisations. There was one anonymous link which was available to all respondents. There were no invitations sent to named individuals – therefore no sampling or data requirements were needed. A number of charities representing more prevalent neurological conditions were sent a unique link that they were able to send to their members. This ensured better monitoring of the number of responses. Specific links were developed for:

- Epilepsy
- Multiple Sclerosis (MS)

Whilst specific links were developed for the above conditions, responses from all conditions were tracked by reporting on question 2 in the survey, which asked respondents to rank their neurological conditions, and answer from the perspective of their primary neurological condition where they had more than one. This was to aid clarity and ensure consistency across responses.

The paper (in-clinic) survey was handed out to patients as they arrived in neurology clinics across England. They were not handed to specific named patients – and no surveys were distributed via post. There was therefore no data requirement and no sample needed preparing in advance of the survey going live.

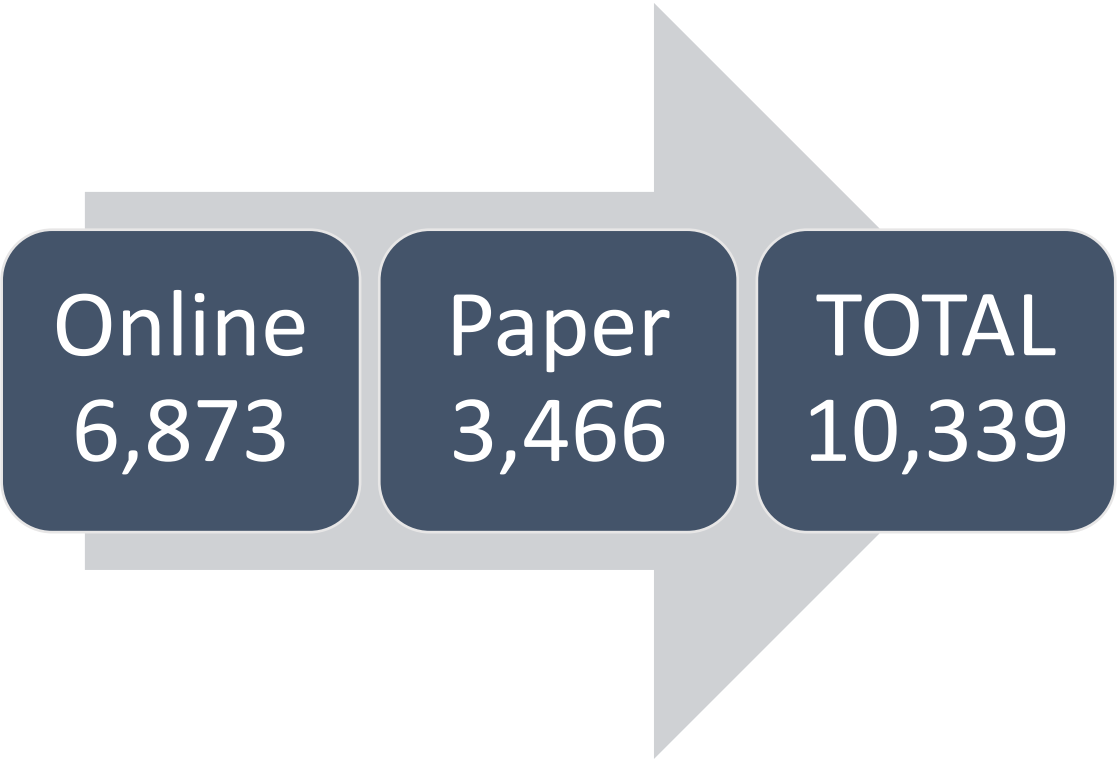
For both methods of data collection there was no sampling or data requirement.

2.4 Timescales and fieldwork

The timescales were as follows:

- **Development of question set:**
    - Steering group meetings and development of questions: Feb – May 2018
    - Cognitive testing of questionnaire: May – June 2018
    - Further refinements to questionnaire: June – July 2018
    - Questionnaire ready for first pilot: July 2018
- **Two pilots to develop and refine methodology:**
    - Pilot 1: 9 July 2018 – 23 July 2018 (Southampton, Poole, Oxford)
    - Pilot 2: 29 October 2018 – 7 December 2018 (Watford, Salford)
- **Full rollout:**
    - Online: 17 October 2018 – 22 March 2019
    - Paper (in-clinic): 21 January 2019 – 22 March 2019

2.5 Response rate



When compared to other national patient experience surveys: over 10,000 responses is a significant achievement for a survey of this type, with no sample used for mailing of questionnaires.

It is therefore considered a significant success.

3. Results of the questionnaires

3.1 Respondent characteristics

3.1.1 Age

Three quarters of respondents (75%) were aged between 35 and 74. 15% of respondents were aged between 18 and 34. Just 2% of respondents were under the age of 18. 7% were aged over 75.

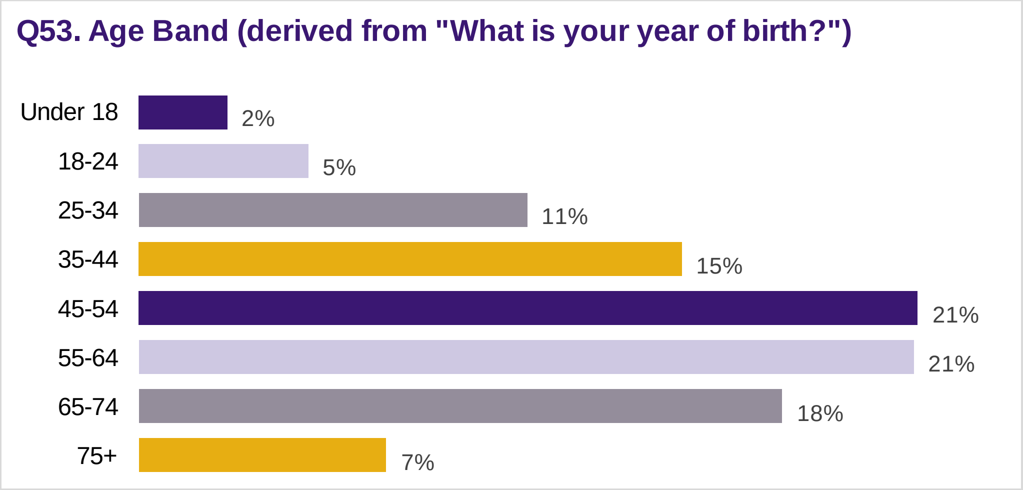


Fig 1. Age range of respondents

3.1.2 Ethnicity

The vast majority of respondents (96%) identified themselves as ‘White’ - either English / Welsh / Scottish / Northern Irish / British – or Irish / other White background.

The numbers of those identifying themselves as Black (including African, Caribbean and other Black background), Asian (including Bangladeshi, Indian, Chinese and other Asian background), Mixed Heritage (including White & Asian, White & Black African, White & Black Caribbean and other Mixed background), Arab or any other ethnicity except White, is very low (just 4%). This compares to 14% of the population in England and Wales (*2011 Census, Office for National Statistics*). When it comes to looking at the data broken down by ethnicity, the conclusions drawn should be used with extreme caution without further empirical investigation.

For the purposes of breaking down the data, respondents who identified themselves as ‘White’ have been grouped together, and all those who identified as Black, or as having another minority ethnic identity (BME), have been grouped together.

3.1.3 Gender

There was an over-representation of female respondents, which is unusual when compared to other national survey programmes. It should be noted that more women than men have a neurological condition, although exact data across all conditions is not available.

6,631 respondents (68% overall) identified themselves as female. Around a third (32% or 3,106) identified themselves as male. 15 individual respondents preferred to use their own term to describe their gender.

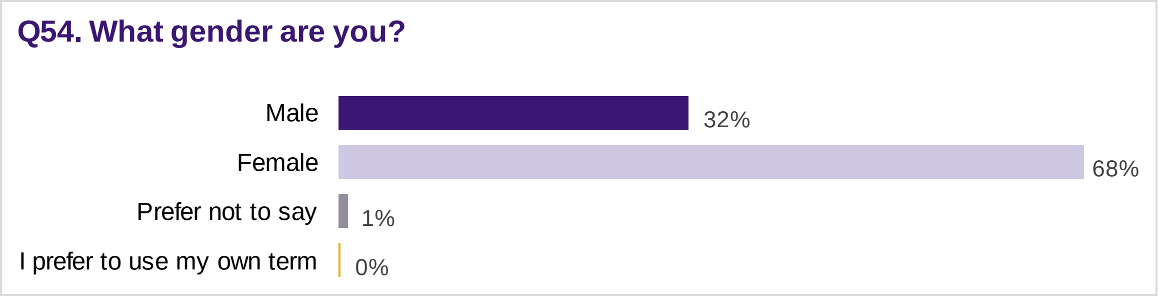


Fig 2. Gender breakdown

3.2 Introductory questions

The majority of respondents (88%) filled in the survey themselves, as the person with a neurological condition (or conditions). 11% were responses from a friend or family member, filling it in on behalf of the person with a neurological condition. Just 1% completed the survey by another means.

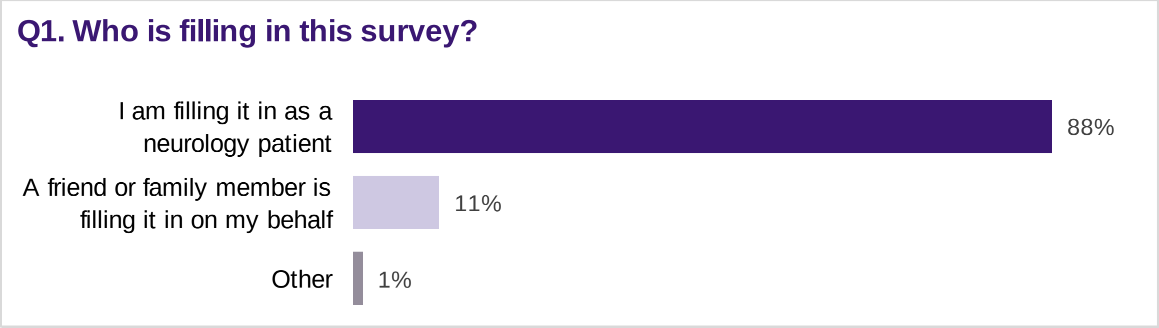


Fig 3. Method of survey completion

3.2.1 Questions about your condition

As the survey was promoted via The Neurological Alliance's member organisations, there was a good representation of a wide range of neurological conditions reported as a primary condition.

Respondents with more than one neurological condition were asked to rank their conditions in order of the extent to which the condition affected their quality of life. One respondent listed 9 conditions and one respondent listed a total of 21 conditions. 6% of respondents reported having multiple primary conditions. These were listed in a separate group to avoid confusion in analysis of the data.

The chart below shows the number of respondents reporting more than one neurological condition.

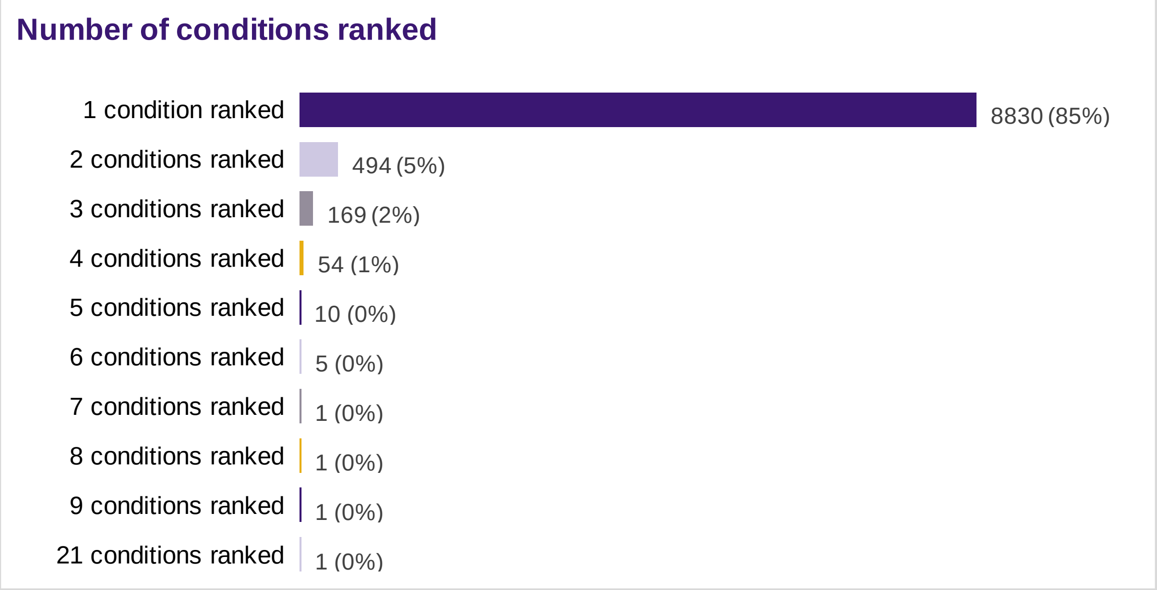


Fig 4. Respondents with multiple neurological conditions

The majority of respondents (85%), listed just one neurological condition.

There was also a free text option for respondents to include a neurological condition not listed as a response option. Extensive data cleansing took place following the end of fieldwork on any free text responses for **primary condition ONLY**. This included:

- Reviewing all responses and standardising spellings / description of condition
- Adding responses to existing response options where appropriate (and removing from 'other')
- Checking with medical professionals in relation to those conditions which were unknown
- Removing inappropriate responses
- Reviewing instances where respondents had listed symptoms rather than neurological conditions.

In addition, all responses were analysed alongside national neurology prevalence data. This analysis is included as Appendix B.

After carrying out this analysis, a decision was made not to weight the data. It is therefore important to acknowledge that there are different levels of representation amongst different conditions. If the weighting factors were applied, the assumption would be that the small number of responses received for underrepresented conditions are representative of the overall condition populations – an assumption which is likely to be incorrect in many instances. For example, it would be unreasonable to assume that the opinions of the 13 respondents for Fibromyalgia are representative of the 1.2m individuals known to have this condition overall.

- The most commonly reported condition was multiple sclerosis (12% of respondents). For primary condition only.
- The second most commonly reported condition was epilepsy (11% of respondents).
- 57% of respondents reported living with another (non-neurological) condition.

The full set of conditions is included with this report as Appendix C. This is where a respondent has listed a neurological condition that they have, even where this is not their ‘primary’ condition and so not the condition they were focusing on for the purpose of answering the survey questions (e.g. about when they were diagnosed). The tree map over the page (Fig. 5) illustrates the breakdown of neurological conditions reported as a primary condition. NB. Only the primary conditions were data cleansed.

Fig 5. Primary condition representation

3.2.2 Quality of life

The data clearly shows the significant impact living with a neurological condition has on the quality of life of respondents.

Almost half of respondents (46%) reported that their neurological condition affected their quality of life to a great extent (the most severe response option). A further 35% reported that their neurological condition affected their quality of life to a moderate extent. Just 3% of respondents reported that their neurological condition did not affect their quality of life at all.

78% of respondents reported that their neurological condition affected their day to day activities to a moderate or great extent.

In terms of pain or discomfort caused by neurological conditions, two-thirds of respondents (66%) reported that their condition caused pain or discomfort to a moderate or great extent.

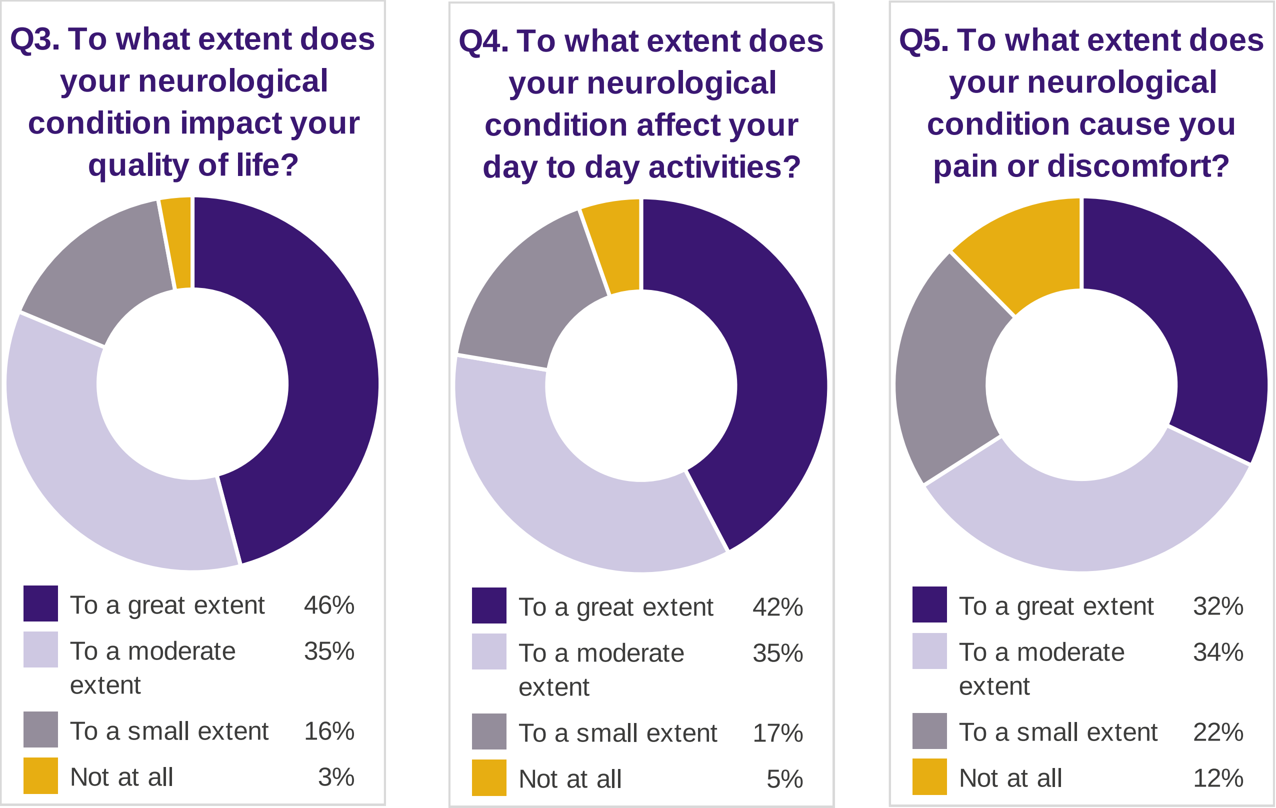


Fig 6. Impact of neurological condition on quality of life

3.3 Before diagnosis

3.3.1 Seeing a GP before diagnosis

The data demonstrates there are issues with diagnosis and referral to specialist neurological services.

However:

- 14% did not see a GP before seeing a neurologist (this includes emergency admissions)

Of the rest:

- 41% saw their GP only once or twice
- 20% saw their GP three or four times
- **39% saw their GP five or more times**

This does not compare favourably with other conditions. Well over a third of respondents have to see their GP five or more times.

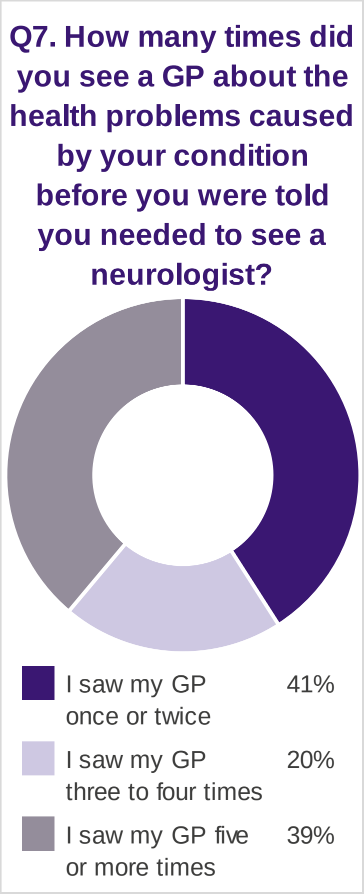


Fig 7. GPs and referrals to specialist neurological services

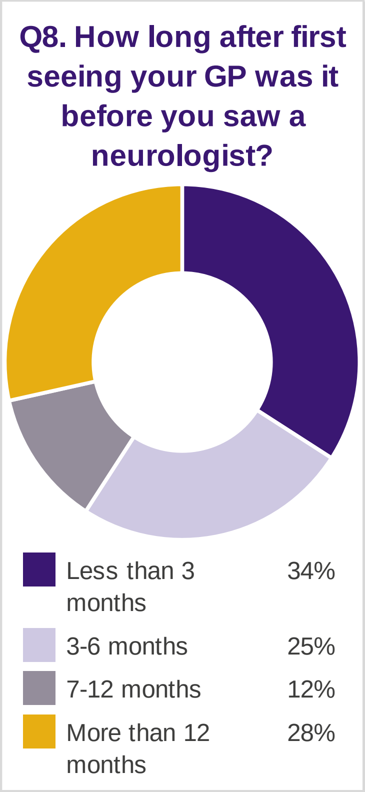


Fig 8. Waiting to see a neurologist

3.3.2 Waiting to see a neurologist

There is an apparent delay between first seeing a GP and seeing a neurologist. This is perhaps unsurprising.

The average length of time between first seeing a GP and seeing a neurologist:

- 34% less than 3 months.
- 25% 3-6 months.
- 12% 7-12 months.
- 28% more than 12 months.

Almost a third of respondents are waiting over a year between seeing their GP and seeing a neurologist.

3.3.3 Waiting for diagnosis

Respondents still face difficulties in obtaining a confirmed and accurate diagnosis for their neurological condition even after seeing a neurologist. Just 24% of respondents were diagnosed immediately upon seeing a neurologist. 38% received a diagnosis in under 3 months. 31% were diagnosed in 3-12 months. However, over a fifth (21%) waited over 12 months for a confirmed and accurate diagnosis.

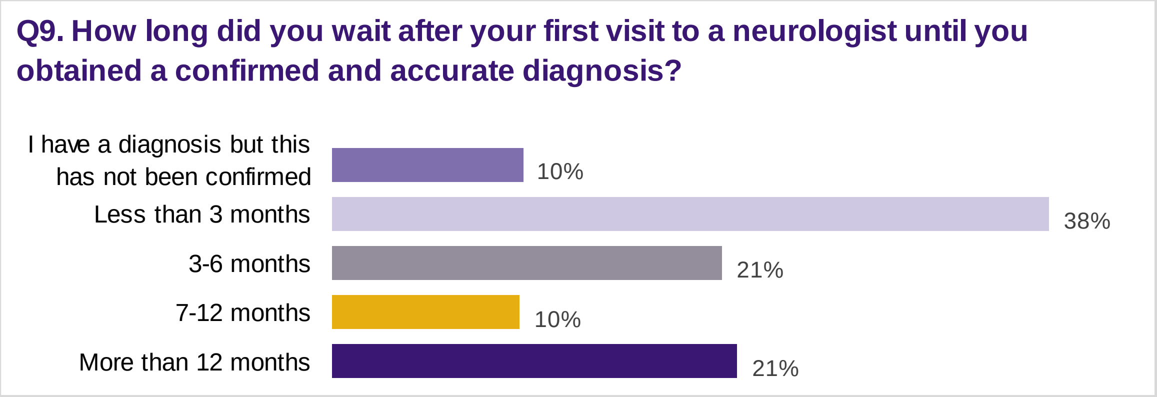


Fig 9. Diagnosis by neurologist

3.4 Diagnosis

3.4.1 When were you first diagnosed?

Almost a third of respondents (32%) were diagnosed with their primary neurological condition over 10 years ago. Of the rest:

- 15% of respondents were diagnosed within the last 12 months.
- 15% of respondents were diagnosed in the last 1-2 years.
- 20% of respondents were diagnosed in the last 3-5 years.
- 18% of respondents were diagnosed in the last 6-10 years.
- 5% of respondents were still waiting to be diagnosed.

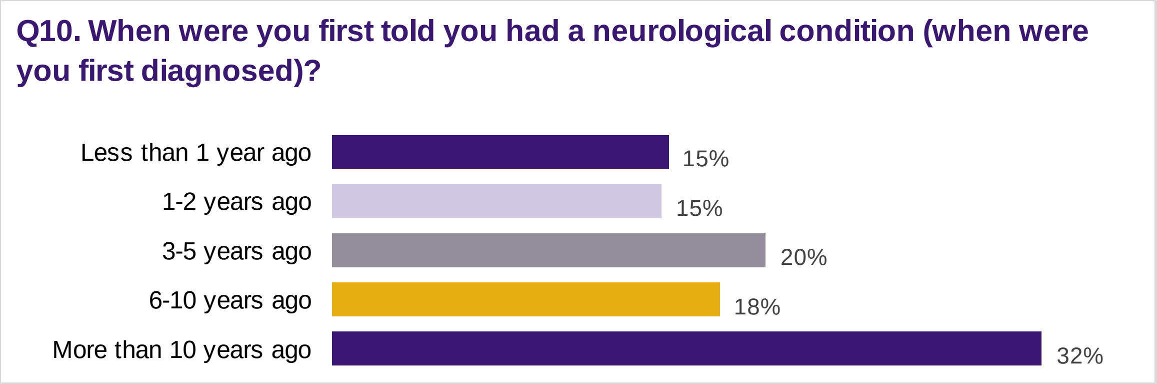


Fig 10. Time since diagnosis

3.4.2 Did you and your family understand the explanation given to you at your diagnosis?

There appears to be a significant issue around the way in which a new diagnosis of a neurological condition is explained to patients.

Only 38% of respondents completely understood the explanation they were given about their condition

39% of respondents understood *some* of the explanation of their condition

12% of respondents did not understand their explanation at all

11% were not given any explanation

3.5 Information about your condition

3.5.1 Written information

As above, there is also a clear issue around provision of written information to individuals following a neurological diagnosis:

- Almost half of respondents (43% - or 4,430 individuals) were **not** offered any form of written information.
- Around a fifth of respondents (21% - or 2,140 individuals) were offered written information produced by the hospital.
- Just 7% were offered written information from a specific charity relevant to their condition.
- 4% of respondents were offered written information from the hospital and information from a specific charity.

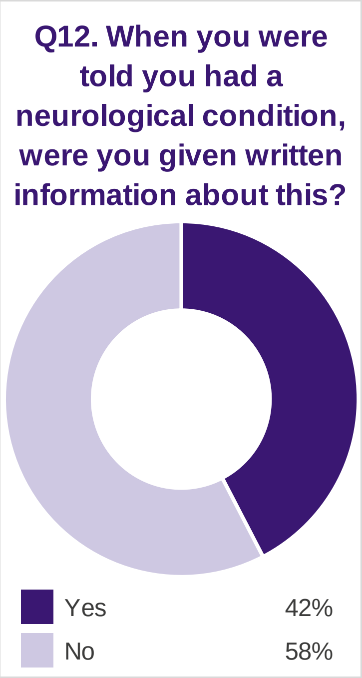
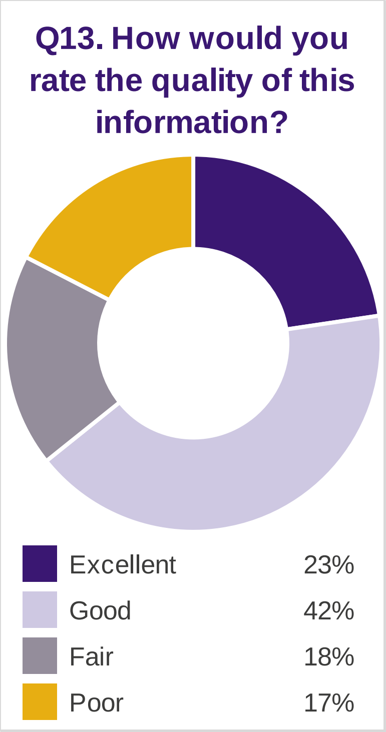


Fig 11. Written information



3.5.2 Quality of information given

Respondents who were offered information were asked to rate the quality of this information. Feedback is positive: almost two-thirds of respondents (64% - or 3,378 individuals) rated the quality of information as either good or excellent. 18% rated it as fair and 17% as poor.

Fig 12. Quality of written information

3.5.3 Finding further information

After receiving a neurological diagnosis, there appears to be an issue with patients being told where they should look for further information about their condition:

- Over half of respondents (56%) were not told anything about finding further information.
- 11% of respondents were told to contact the hospital for further information.
- 11% of respondents were told to contact a specific charity.
- 15% of respondents were told to look at a specific website on the Internet.
- 6% of respondents were told to simply look ‘on the Internet’.
- Almost a fifth of respondents don’t know or can’t remember if they were told anything. Research suggests this usually means they were not told anything.

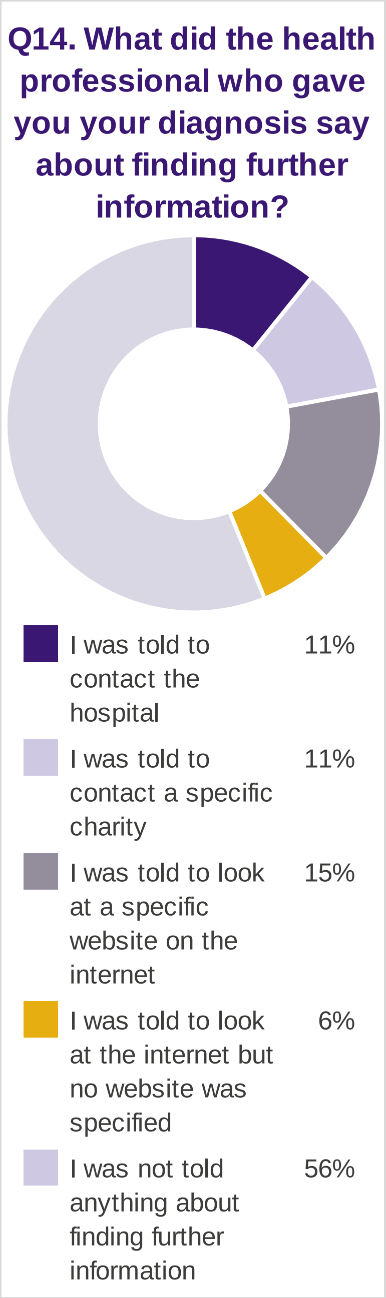


Fig 13. Finding further information

Where respondents looked on the Internet to find further information, the sites which consistently proved most useful were specific charities: almost a third of respondents (32%) reported finding a website of a particular charity most useful. This compares to: 26% who found information on the NHS website most useful, 16% who found social media most useful, 5% who found patient.co.uk most useful, and 3% who found Net Doctor most useful.

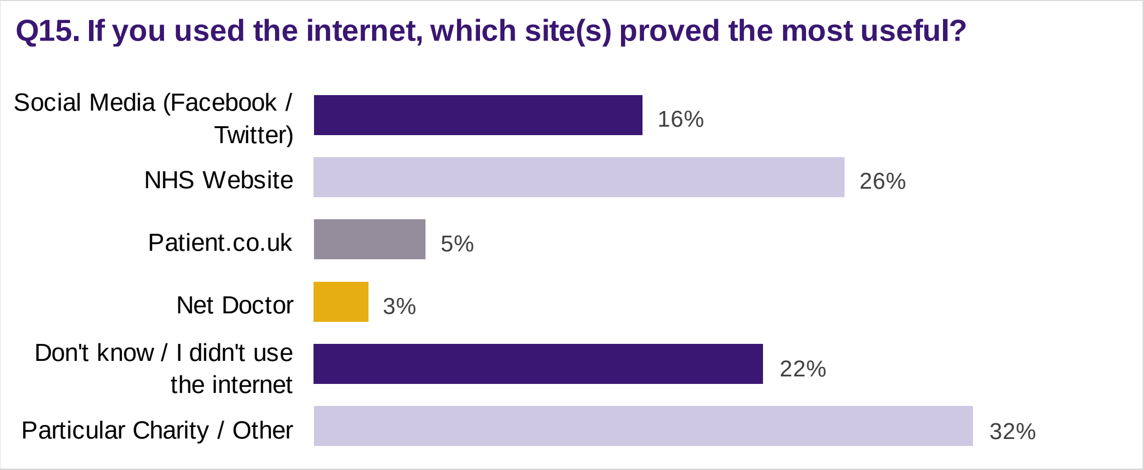


Fig 14. Websites respondents found most useful

3.6 Treatment and care

3.6.1 How long until treatment started

Almost half of respondents (46%) reported that the treatment for their neurological condition started immediately after diagnosis. Of the others:

- Almost a fifth of respondents (17%) said they were treated within a month of diagnosis.
- 9% of respondents said they were treated within 1-2 months of diagnosis.
- 9% of respondents said they were treated within 3-4 months of diagnosis.
- 5% of respondents said they were treated within 5-6 months of diagnosis.
- 5% of respondents said they were treated within 7-12 months of diagnosis.
- 10% of respondents said they **waited over a year** before being treated for their neurological condition.

In addition:

- 1% of respondents who have been offered treatment report declining this treatment.
- 8% of respondents report still waiting for their treatment to start.
- 12% of respondents report there is no treatment for their condition.

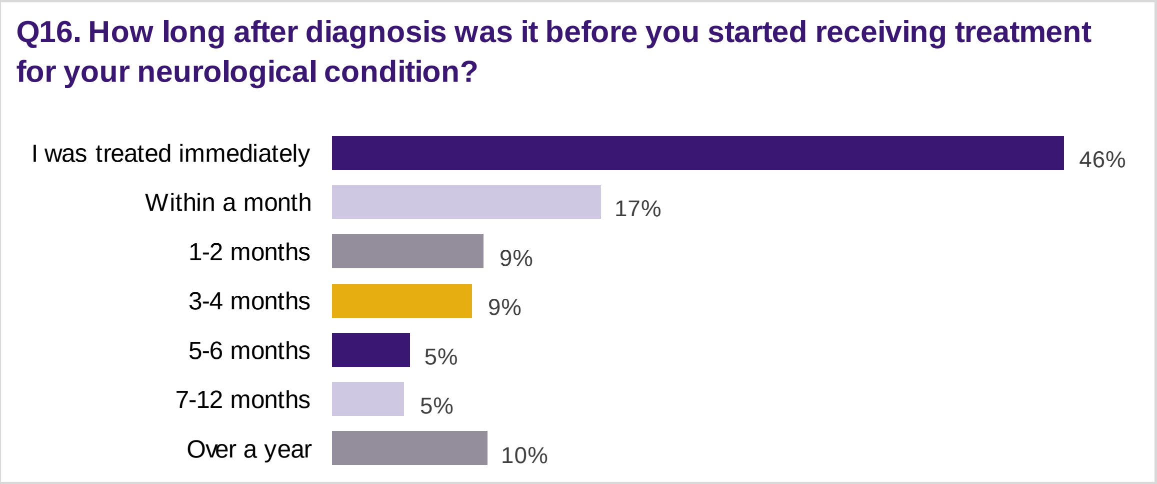


Fig 15. Waiting for treatment to start

3.6.2 Medication

Almost three-quarters of respondents (73%) took regular medication to manage their neurological condition. Of this, over half of respondents (54%) took medication that they did not have to pay for. Almost a fifth of respondents (19%) took medication and also paid for it.

Respondents were also asked about non-prescribed medication or substances that they might use to manage their neurological condition. Over a quarter of respondents (27%) reported taking non-prescribed medication to manage their condition.

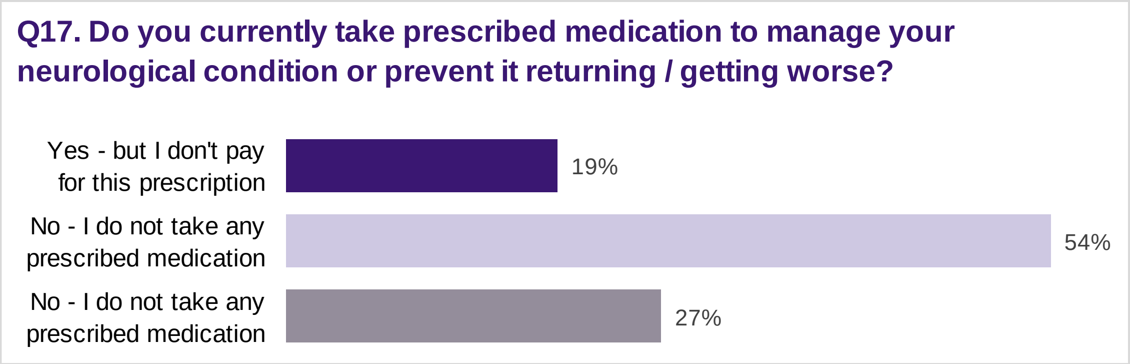


Fig 16. Medication and prescriptions

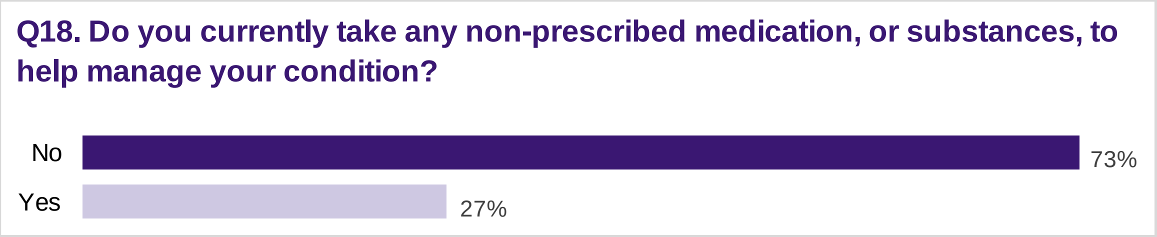


Fig 17. Non-prescribed medication

3.6.3 Neurological Nurse Specialists (CNS)

As seen in other condition-specific patient experience surveys, respondents generally report favourably on their experiences of specialist nurses. 39% of respondents had access to a nurse specialist for their specific neurological condition. Almost the same amount (38%), did not have access to a specialist nurse and would like to have access to one. Around a quarter of respondents (24%) did not want or need to see a specialist nurse for their condition.

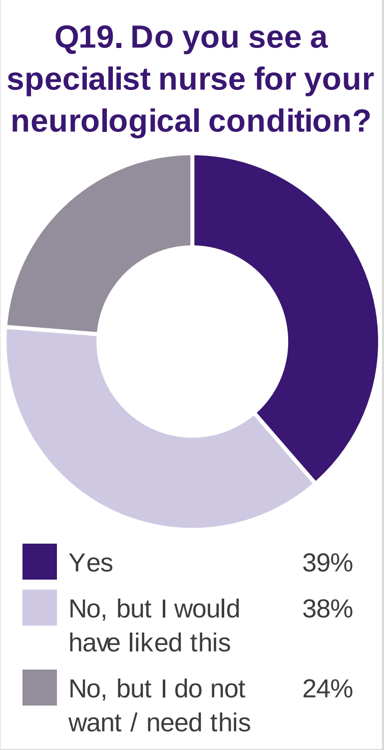


Fig 18. Access to Clinical Nurse Specialists

3.6.4 Assistive equipment

Just under a third of respondents (30%) had seen a health professional for help with assistive equipment.

Of those who were recommended assistive equipment to help with day to day tasks:

- Over half (52%) received the equipment via the NHS.
- Over a fifth (22%) funded this purchase themselves.
- Almost a third (28%) received funding for the assistive equipment from their local authority.
- 4% accessed a grant from a charity.
- Just 1% also fundraised for the equipment.
- 1% of respondents (33 individuals) reported not being able to afford the equipment so they do not have it.

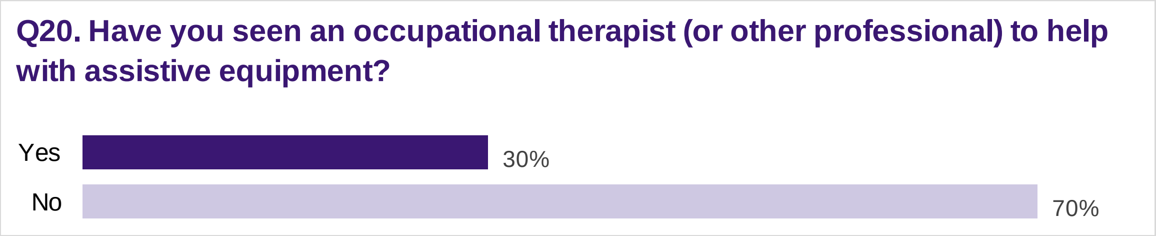


Fig 19. Access to assistive equipment

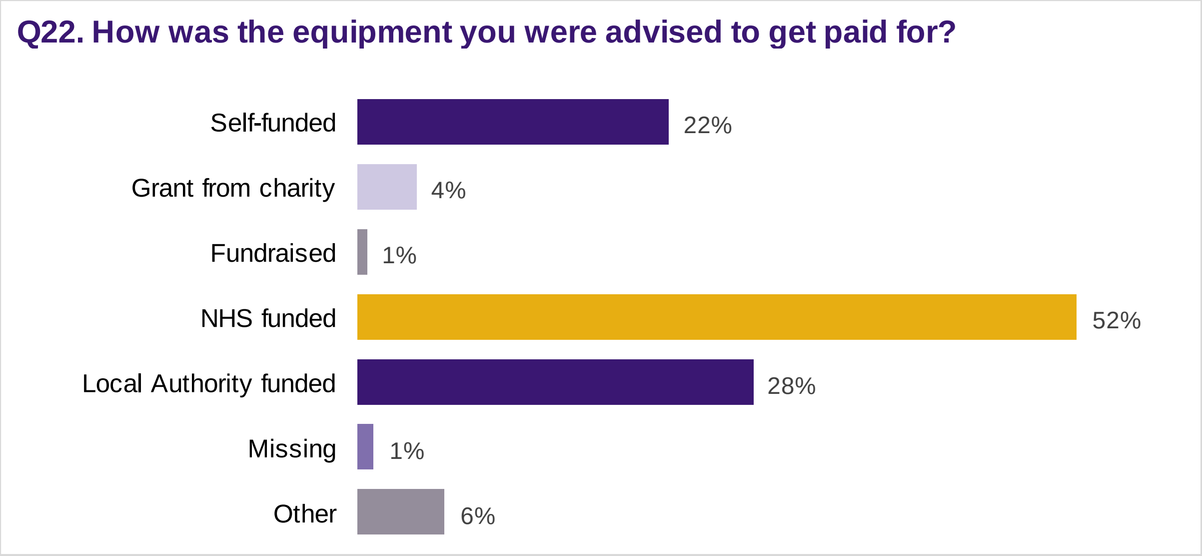


Fig 20. Funding for assistive equipment

3.6.5 Therapies

Respondents were asked which therapies they had been offered as part of the treatment for their neurological condition. Almost half of respondents (44%) had not been offered any form of therapy for their neurological condition. The most common forms of therapy offered to respondents were physiotherapy (33%), occupational therapy (16%) and speech and language therapy (13%). Just 11% of respondents were offered counselling. The chart below shows this in more detail.

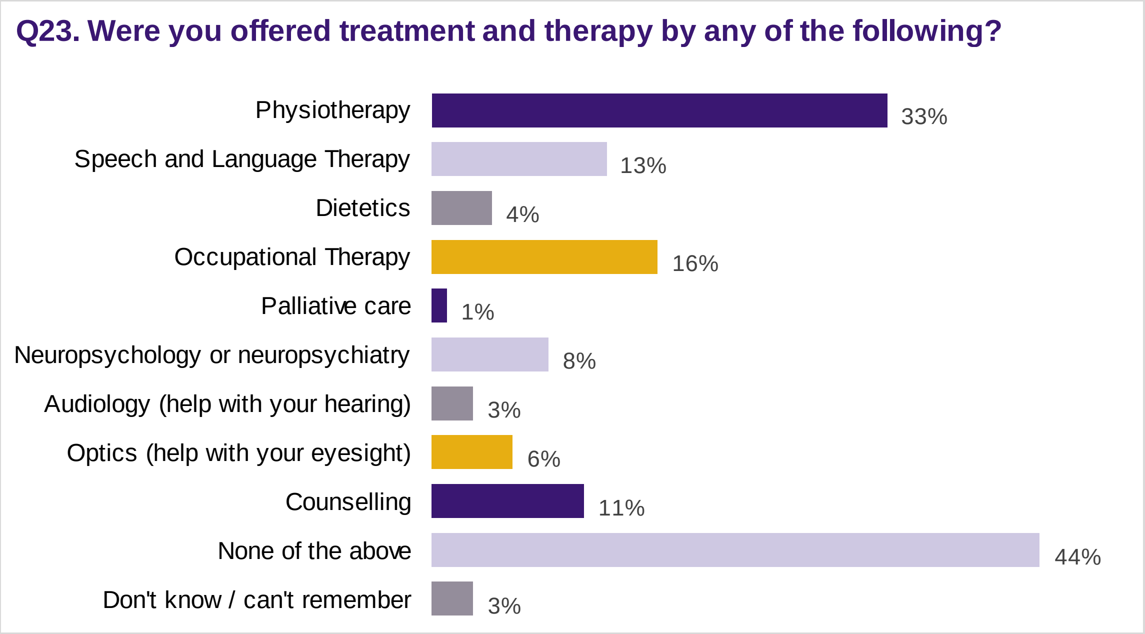


Fig 21. Treatments and therapies offered to respondents

Respondents were then asked which therapies they would have liked but were not offered. Aside from the response option ‘none of the above’, Counselling was the most popular response: over a fifth of respondents (22%) would have liked counselling but were not offered any.

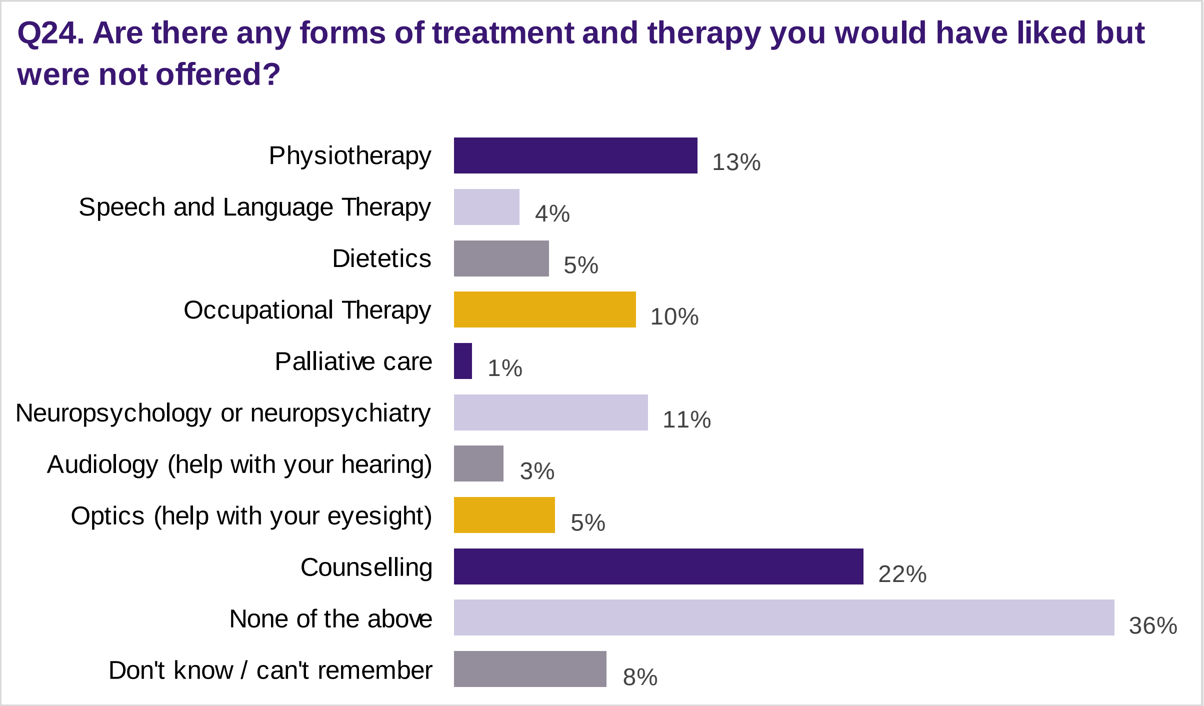


Fig 22. Therapies respondents would have liked

3.7 Hospital care

3.7.1 Admissions to hospital

The majority of respondents (80%) reported having had no planned admission to hospital in the past two years. Of the others, 14% of respondents had had 1-2 planned admissions, 3% had had 3-5 admissions, 1% had had 6-9 admissions and a further 1% had had 10 or more admissions.

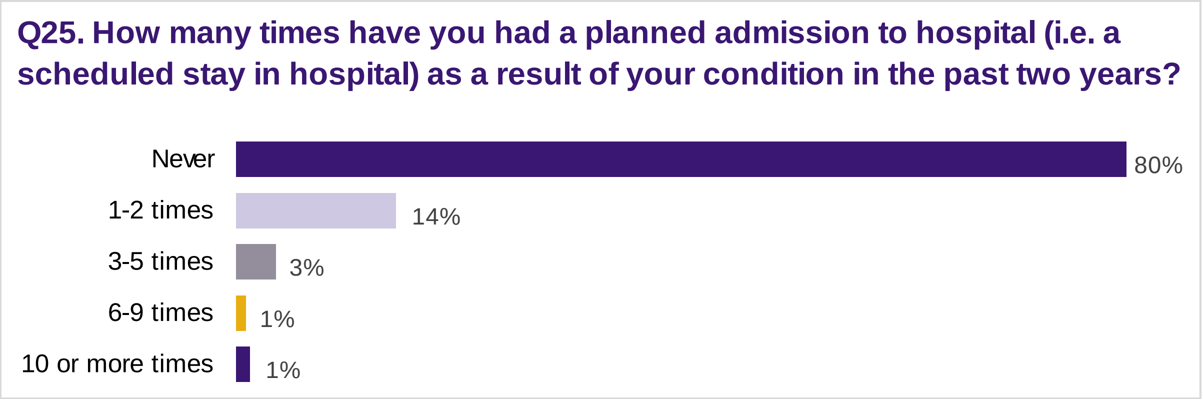


Fig 23. Planned hospital admissions

3.7.2 Emergency admissions

Almost three quarters of respondents (71%) reported having had no emergency admission to hospital as a result of their neurological condition in the last two years. However, over a fifth (21%) had been admitted as an emergency between 1 and 2 times.

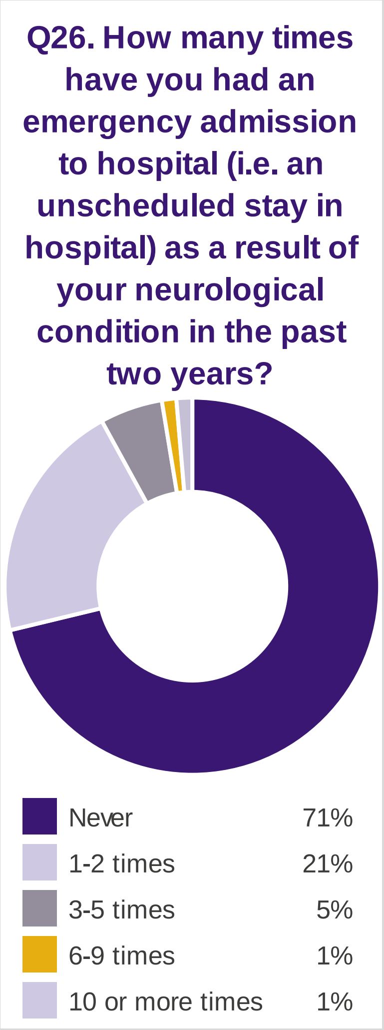
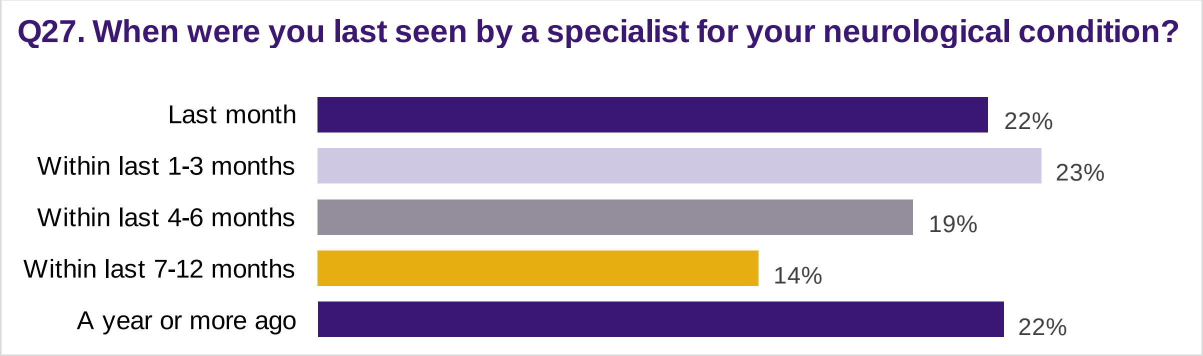


Fig 24. Emergency admissions

3.7.3 Specialist neurological care

Over a fifth of respondents (22%) were seen by a neurologist within the last month. Just 7% had never been seen by a specialist in hospital for their condition.

Fig 25. When were respondents last seen by a neurologist



Almost half of respondents (49%) reported being seen often enough for their needs. Just over a third (34%) reported that they would like to be seen more frequently to help meet their needs.

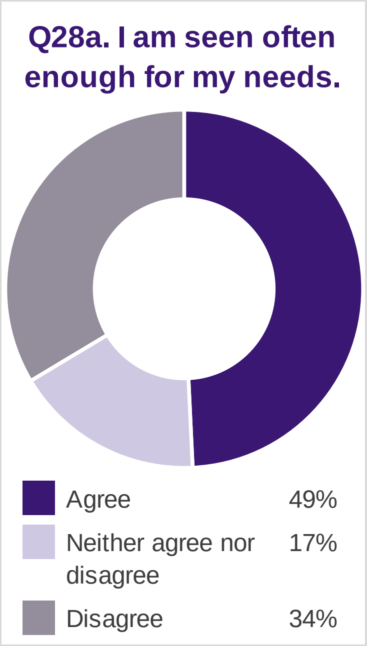


Fig 26. Respondents being seen often enough for their needs

3.7.4 Satisfaction with specialist care

Half of respondents reported being satisfied with their specialist neurological care. Around a fifth were undecided, but well over a quarter (28%) reported being dissatisfied with the care they were receiving for their neurological condition.

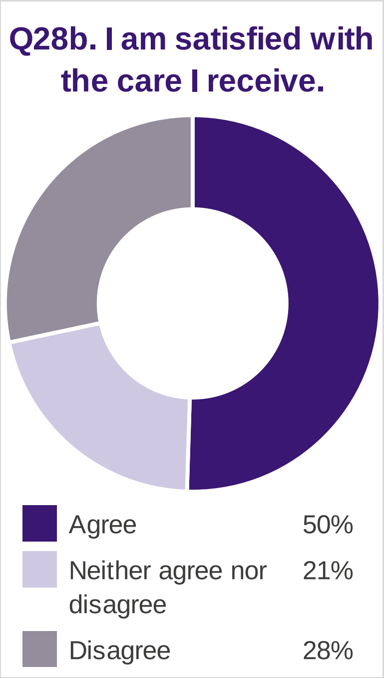


Fig 27. Satisfaction with specialist care

3.7.5 Specialist neurological care and the people around you

Over half of respondents (52%) agreed that information about their specialist treatment and their condition is effectively passed on to the people that care for them (such as their GP, nurse, or family carer). 28% of respondents however, felt that this information was not effectively passed on.

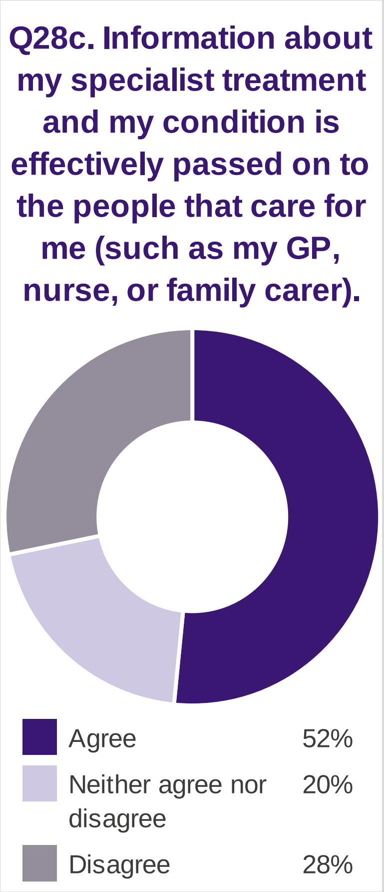


Fig 28. Specialist neurological care and the people around you

3.7.6 Satisfaction with care at home following a hospital visit

Respondents reported being dissatisfied with the level of care they received at home following a hospital visit. Well over a third of respondents (40%) reported that the care they received at home following a hospital visit did not meet their needs.

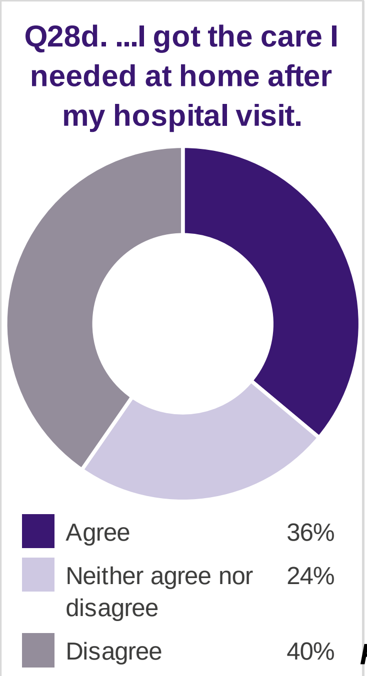


Fig 29. Satisfaction with home care following a hospital visit

3.8 Support for your neurological condition

3.8.1 Care plans

There appears to be an issue surrounding care plans. They are not being offered to patients as widely as possible, and they appear to be widely misunderstood. Just 11% of respondents had a care plan. These are mainly issued by the health team that look after the neurological patient. Almost a third of respondents (28%) report not having a care plan but wanting to have one. Well over a third (36%) report not needing a care plan, and almost a fifth (17%) report not knowing what a care plan is.

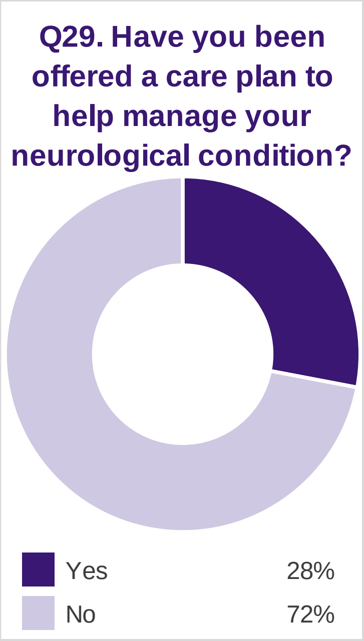


Fig 30. Care plans

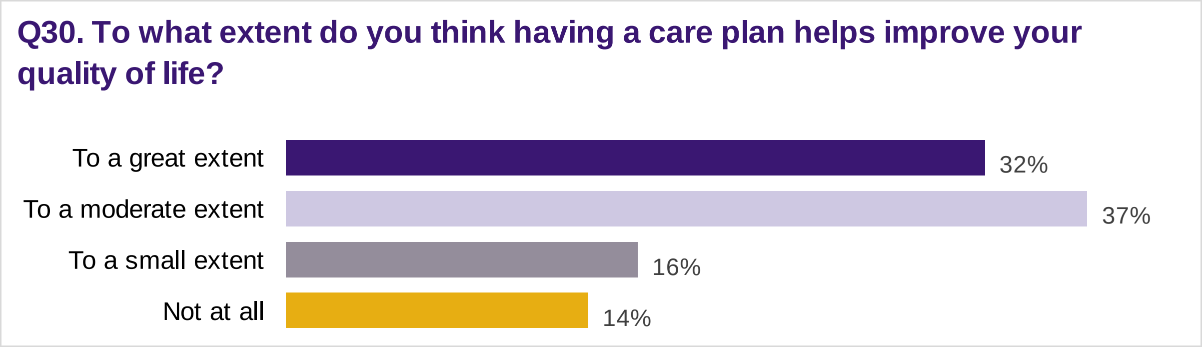


Fig 31. Care plans and quality of life

3.8.2 Mental and emotional wellbeing

Well over half of respondents (58%) had not been asked about their mental health or emotional wellbeing as a result of living with their neurological condition. Just over a quarter of respondents (26%) had been referred to a health professional for their mental or emotional wellbeing. Almost a third of respondents (30%) were not referred but would have liked to have been.

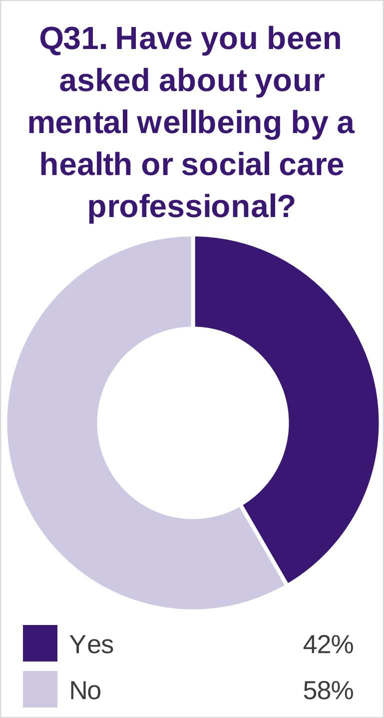


Fig 32. Mental and emotional wellbeing

Fig 33. Referrals for professional emotional or wellbeing support

Of those who were referred, this was most commonly to a counsellor or psychotherapist.

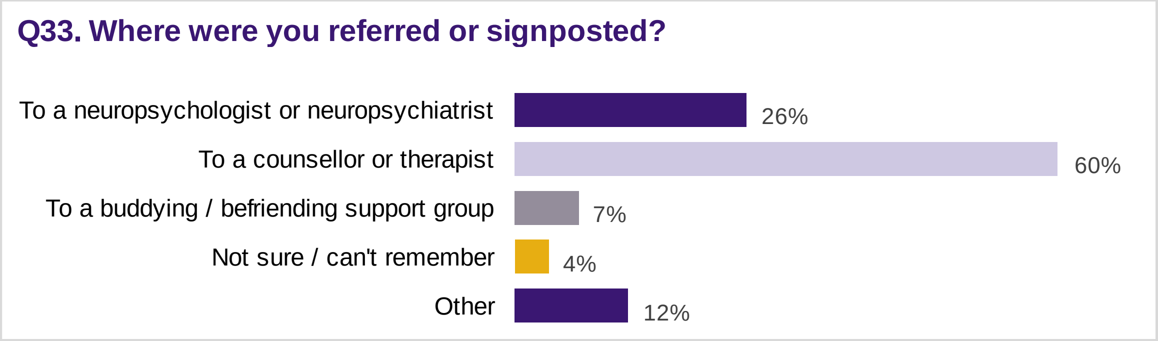


Fig 34. Where were respondents referred or signposted

Of those who were referred for professional emotional support, the majority reported finding it helpful.

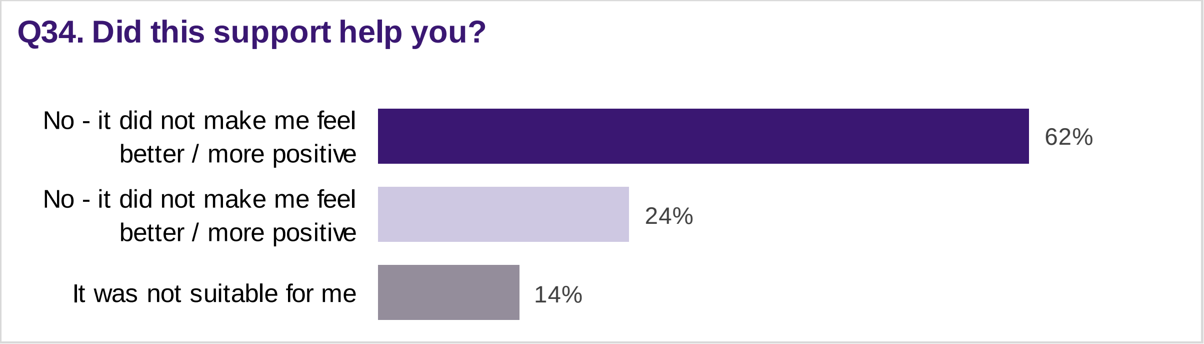


Fig 35. Did the support help?

Finally in this section, the survey asked respondents if they felt their mental or emotional needs were being met. It would appear that the majority of respondents do not feel their mental or emotional needs are being met, and there is considerable work to do in this area.

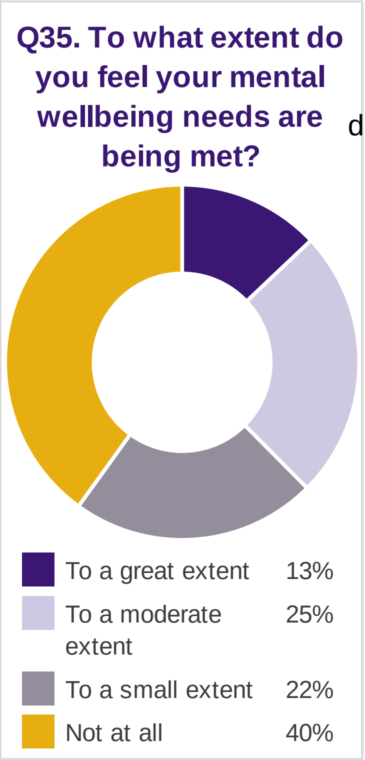


Fig 36. Are emotional and mental wellbeing needs being met?

3.9Social care

3.9.1 Care from friends or family

Over half of respondents (55%) did not receive any care from a friend or family member. However, of the remainder: 43% received care from a friend or family member who was over the age of 18. Just 2% received care from a family member who was under the age of 18.

Fig 37. Care from a friend or family member

3.9.2 Support from your local authority

The vast majority of respondents (81%) had not been assessed by their local council to see if they were eligible to receive care or support.

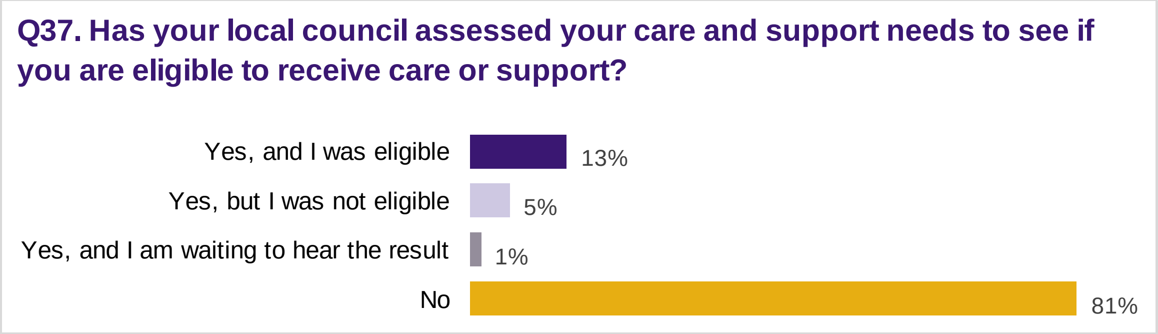


Fig 38. Council assessments for care and support

Well over a quarter of respondents (28%) felt that their care and support needs were not being met at all. Furthermore, over a fifth (21%), felt that their care and support needs were only being met to a small extent. Just a quarter (25%) felt their care and support needs were being fully met.

Fig 39. Extent to which care and support needs are being met

3.9.3 Carers' assessments

Of those respondents who had someone acting as a carer for them, the vast majority (85%) had not had a carers' assessment.

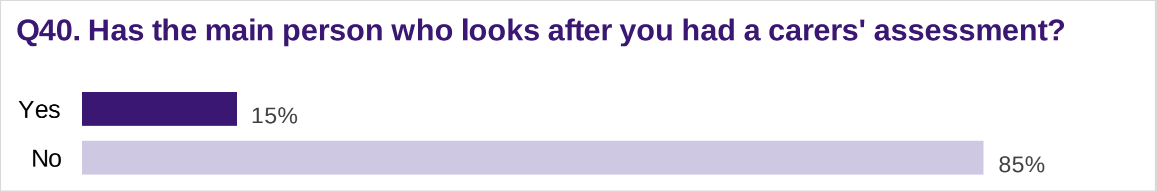


Fig 40. Carers' assessments

Of those who had a carers' assessment, over half (52%) did not go on to receive any additional support.

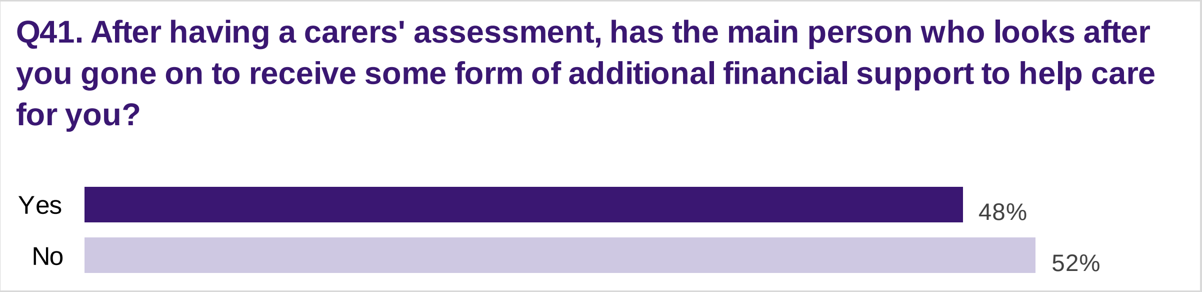


Fig 41. Support following a carers' assessment

3.10 Welfare

3.10.1 Employment, education and training

Over half of respondents (53%) were not in education, employment or training.

Of the remaining respondents:

- 34% were in employment
- 6% were in education
- Just 49 individual respondents were in training

Following diagnosis of a neurological condition, almost two thirds (61%) felt that they could not continue work as normal.

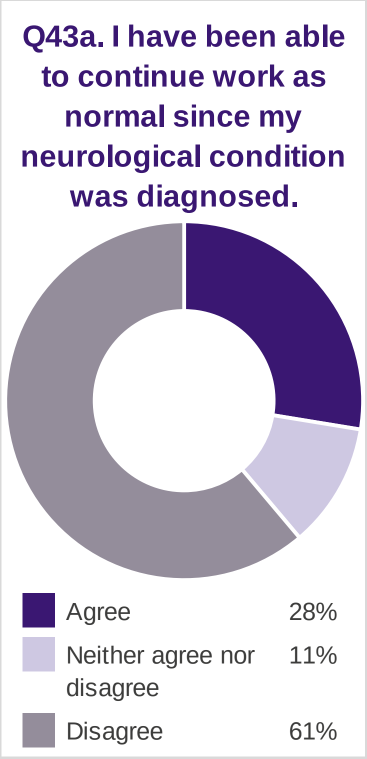


Fig 42. Employment status following diagnosis

Almost half of respondents (48%) felt that their employer had adequately supported them following their diagnosis of a neurological condition. However, almost a third (31%) disagreed, and felt their employer had not been supportive following their diagnosis.

It was clear from respondents that their employment had been severely affected following the diagnosis of their neurological condition. In particular:

- Over a third of respondents (36%) had chosen to **leave work** due to their neurological condition.
- Over two thirds of respondents (68%) had **missed out on opportunities** to develop their career following their diagnosis.
- Well over a third of respondents (38%) had **taken early retirement** as a result of their neurological condition.
- Over half of respondents (54%) could **no longer carry out their job** due to the effects of their neurological condition.
- Over a third of respondents (35%) had been **discriminated against** due to their condition.
- Almost a third of respondents (29%) had their **contract of employment terminated** due to their neurological condition.

Fig 43. Support of employer following diagnosis

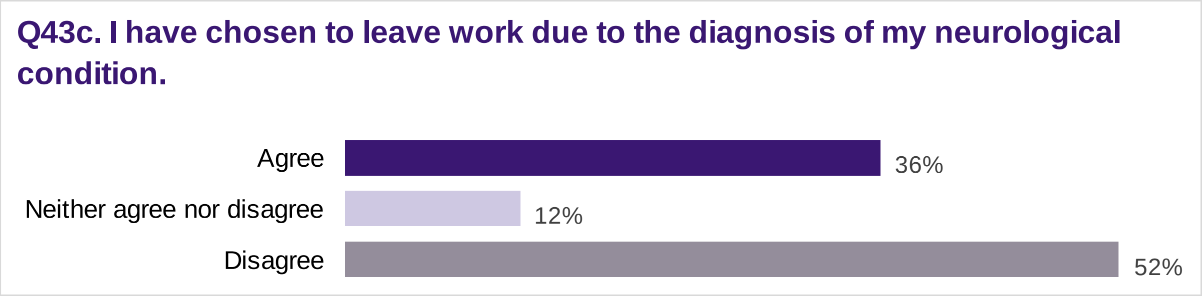


Fig 44. Respondents choosing to leave work due to their diagnosis

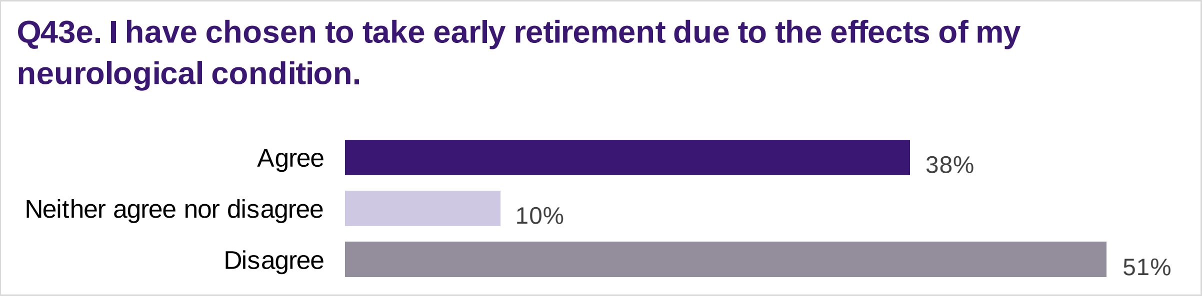


Fig 45. Early retirement due to neurological condition

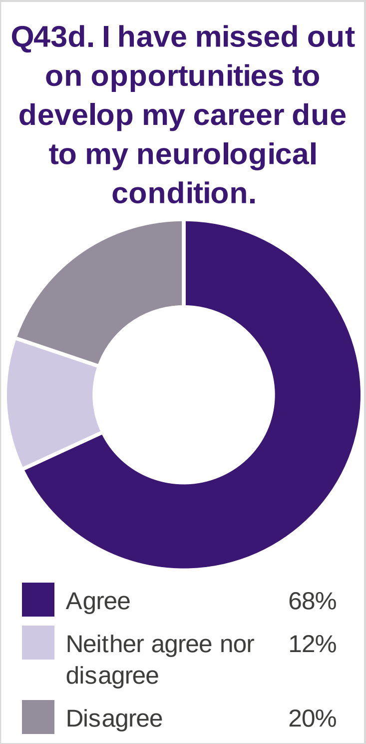


Fig 46. Missed career development opportunities as a result of a neurological condition (above left)

Fig 47. Respondents no longer able to carry out their job due to their neurological condition (above right)

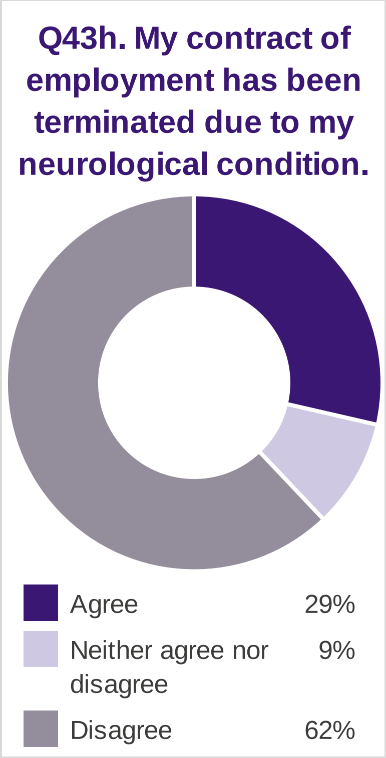


Fig 48. Discrimination due to a neurological condition (above left)

Fig 49. Contract termination due to a neurological condition (above right)

3.10.2 Benefits

Over a third of respondents (38%) were not in receipt of any kind of benefit. The chart below details the range of different benefits accessed by respondents.

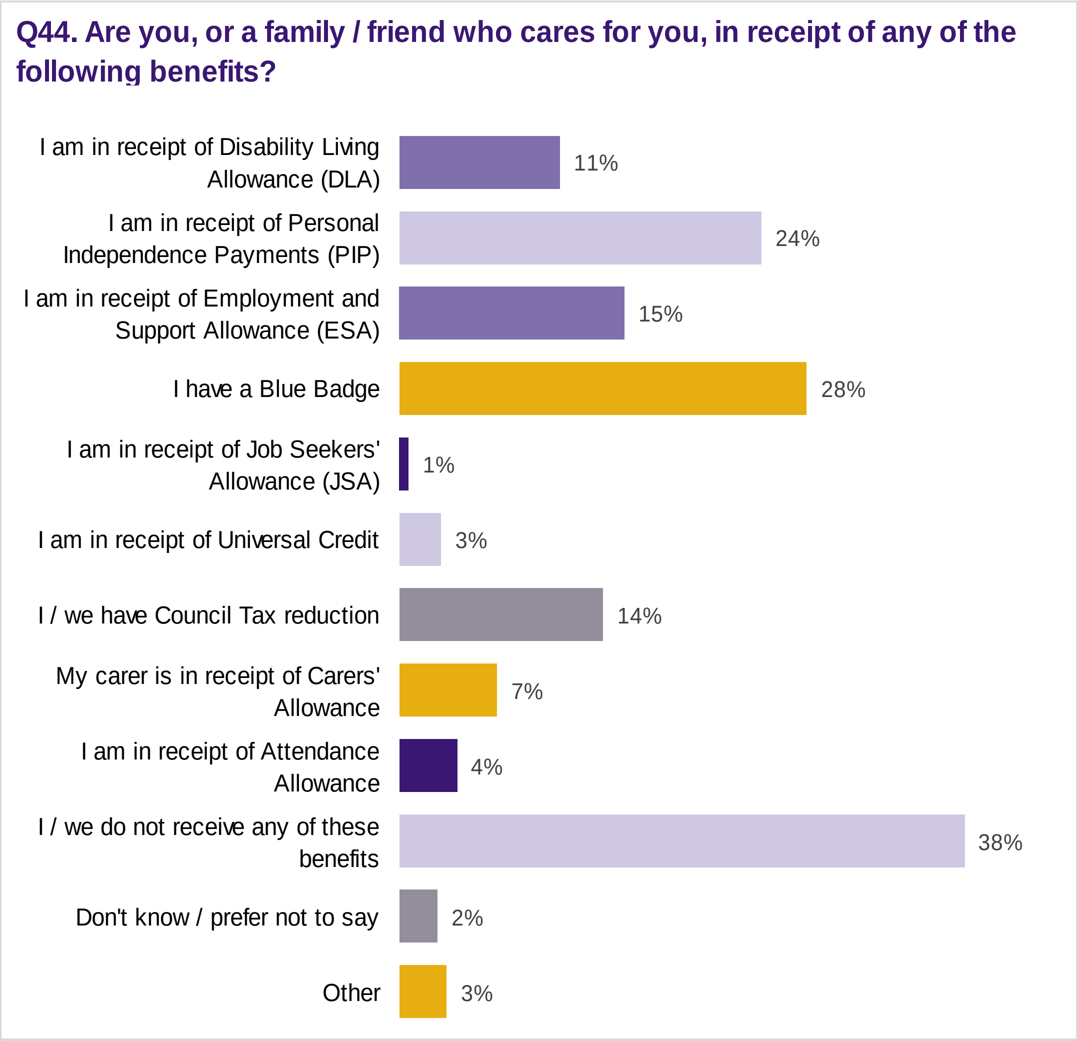


Fig 50. Benefits accessed by respondents

3.10.3 Financial needs

Almost half of respondents (43%) felt that their financial needs were not being met as a direct result of living with a neurological condition.

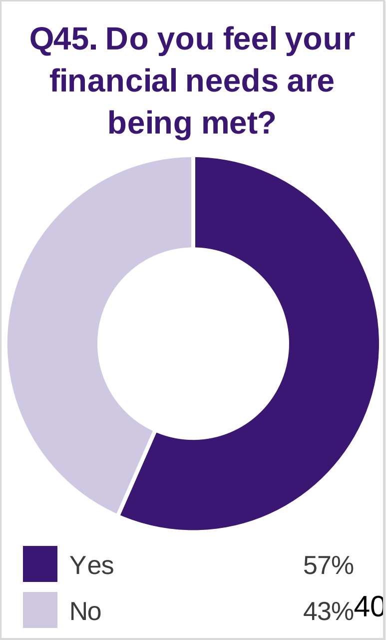


Fig 51. Financial needs

3.11 Health and social care in general

3.11.1 Involvement in care

Respondents felt more involved in their choices about health care than social care. 70% of respondents felt involved in making choices about their health care, at least to some extent. This compares to 58% of respondents who felt involved in making choices about their social care, at least to some extent.

Fig 52. Involvement in health care (above left)

Fig 53. Involvement in social care (above right)

3.11.2 Problems or delays

However, patients were far more likely to experience delays in accessing health care rather than social care. Well **over** half of respondents (55%) had experienced delays in accessing health care. This compares to well **under** half of respondents (43%) who experienced delays in accessing social care.

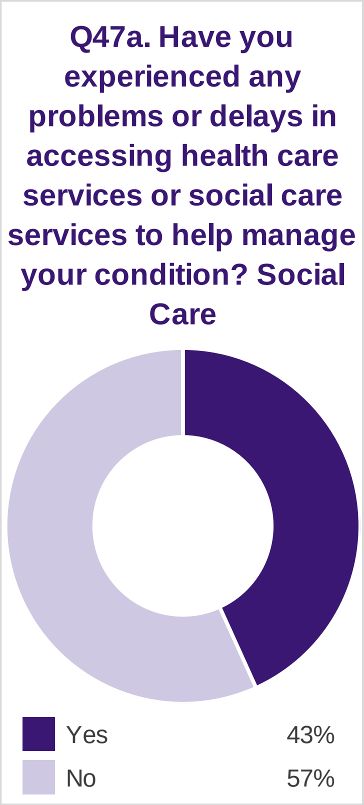
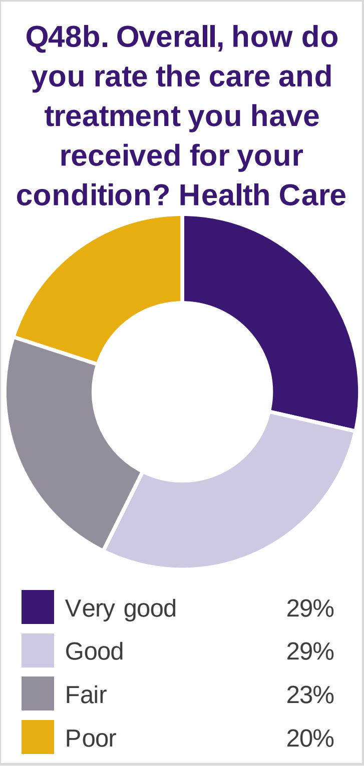


Fig 54. Problems or delays in accessing health care (above left)

Fig 55. Problems or delays in accessing social care (above right)

3.11.3 Overall health and social care

Respondents were asked to rate their overall health and social care they had received as a result of their neurological condition. Respondents were more positive about health care than social care:



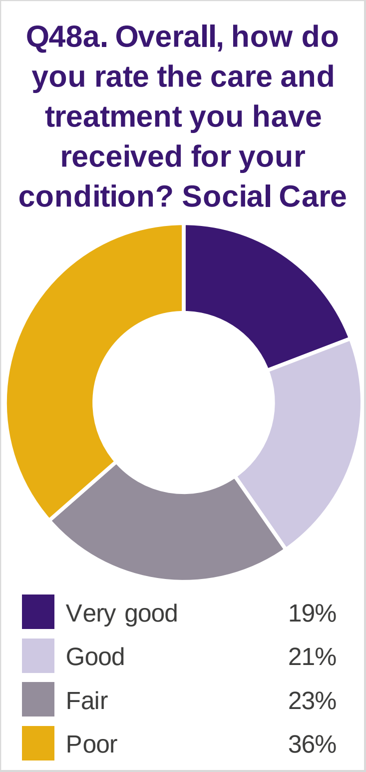


Fig 56. Overall ranking of health care (above left)

Fig 57. Overall ranking of social care (above right)

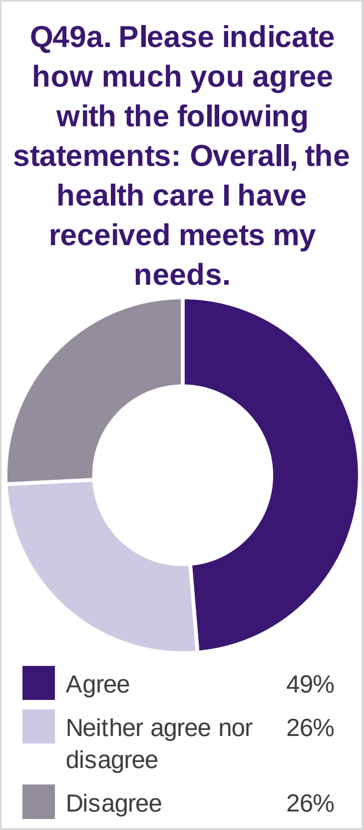
Finally, respondents were asked how much they agreed or disagreed with the statements:

"Overall the health care I have received meets my needs."

And

"Overall, the social care I have received meets my needs."

The charts below illustrate how respondents reacted to these statements. Again, respondents were more positive about health care.



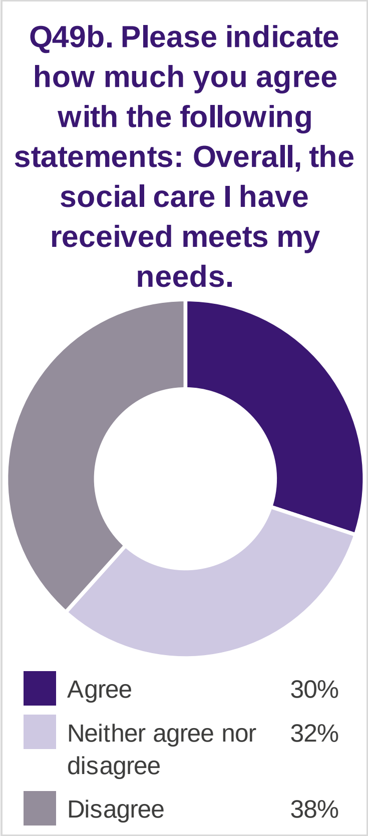


Fig 58. Health care meeting the needs of respondents (above left)

Fig 59. Social care meeting the needs of respondents (above right)

4. Data breakdown analysis

To identify issues where individuals may be need of additional services and support, further analysis was undertaken using the following key variables:

- Neurological condition
- Clinic breakdown (by clinics that took part and achieved the minimum level of response)
- Geography (by STP)
- Age
- Ethnicity
- Gender
- The person who completed the survey (individual with a neurological condition, or family/friend/carer).

In addition, the data was cross tabulated to gain greater insights, with a particular focus on:

- Provision of information (written or otherwise)
- Time taken to be diagnosed (including visits to GPs)
- Understanding of conditions/diagnosis

4.1 Neurological condition

The data was broken down by neurological condition, and the different ways in which respondents scored each question was analysed. As one might expect, there were significant differences according to the neurological condition of the respondent in question.

Where there were enough respondents who were living with a specific neurological condition (see suppression rules), the table below presents neurological conditions in order of how they affect the quality of life of the respondent. From the most severe to the least severe, as reported by respondents to the survey. **Please note that the scoring methodology (full details in Appendix A), is such that a higher score is considered more positive. Therefore, those with the lowest percentage scores indicate the most severe impact on quality of life.**

The table below therefore shows that respondents reported Myalgic encephalomyelitis (ME)/ chronic fatigue syndrome as having the most severe impact and Cavernoma as having the least severe impact. This is as reported from the base sizes below.

Rank	Condition	Base	Score
1	Myalgic encephalomyelitis/chronic fatigue syndrome	319	6.7%
2	Multiple system atrophy	83	8.3%
3	Progressive supranuclear palsy	33	9.0%

4	Post-Polio syndrome	28	9.4%
5	Functional neurological disorder	385	9.9%
6	Traumatic spinal injury	30	9.9%
7	Ataxia	185	12.7%
8	Narcolepsy	100	13.2%
9	Motor neurone disease	134	13.6%
10	Spinal condition	31	14.9%
11	Cerebral palsy	28	16.5%
12	Huntington's disease	40	16.5%
13	Traumatic brain injury	43	16.9%
14	Multiple primary conditions	564	17.5%
15	Trigeminal neuralgia	88	18.0%
16	RLS	279	18.8%
17	Cluster headache	61	18.9%
18	Chiari malformation	40	19.8%
19	Dementia - other (incl. frontotemporal / Lewy body / vascular)	33	20.0%
20	Migraine	718	20.1%
21	Acquired brain injury	104	20.3%
22	Muscular dystrophy	26	21.6%
23	Transverse myelitis	162	22.2%
24	Autoimmune encephalitis	21	23.6%
25	Spina bifida	22	24.0%
26	Dystonia	524	24.5%
27	Other	536	24.8%
28	Idiopathic intracranial hypertension	264	24.9%
29	Essential tremor	75	25.1%
30	Charcot-Marie-Tooth disease	45	25.7%
31	Stroke	127	26.3%
32	Peripheral neuropathy	49	27.0%
33	Chronic inflammatory demyelinating polyneuropathy	68	27.2%
34	Parkinson's disease	842	27.2%
35	Encephalitis	40	27.2%
36	Tourette syndrome	107	27.8%
37	Multiple sclerosis	1188	28.6%
38	Hydrocephalus	59	29.1%
39	I am awaiting diagnosis	584	30.3%
40	Myasthenia	277	30.7%
41	No primary condition	262	33.3%
42	Hemifacial spasm	41	36.2%
43	Epilepsy	1140	36.5%
44	Guillain-Barré syndrome	159	36.8%
45	Brain tumour	102	41.2%
46	Acoustic neuroma	32	43.4%
47	Cavernoma	87	44.1%

Fig 60. Impact on quality of life by neurological condition (above)

The next table (continues on the following page) shows a breakdown on how various conditions affect the respondents’ ability to carry out day to day activities. Presented from most severe impact, to least severe impact.

Rank	Condition	Base	Score
1	Myalgic encephalomyelitis/chronic fatigue syndrome	319	6.6%
2	Multiple system atrophy	83	8.3%
3	Traumatic spinal injury	30	9.9%
4	Post-Polio syndrome	28	10.6%
5	Ataxia	183	10.8%
6	Functional neurological disorder	383	11.1%
7	Cerebral palsy	26	11.4%
8	Motor neurone disease	135	11.5%
9	Progressive supranuclear palsy	33	12.0%
10	Huntington's disease	38	13.0%
11	Narcolepsy	100	15.2%
12	Traumatic brain injury	43	16.9%
13	Spinal condition	31	17.0%
14	Muscular dystrophy	26	17.8%
15	Multiple primary conditions	566	21.4%
16	Chiari malformation	40	21.5%
17	Charcot-Marie-Tooth disease	45	22.0%
18	Cluster headache	61	23.3%
19	Trigeminal neuralgia	88	23.3%
20	Transverse myelitis	160	23.5%
21	Autoimmune encephalitis	21	23.6%
22	Dementia - other (incl. frontotemporal / Lewy body / vascular)	32	23.7%
23	Acquired brain injury	104	24.5%
24	Migraine	717	25.0%
25	Spina bifida	22	25.6%
26	Chronic inflammatory demyelinating polyneuropathy	68	27.2%
27	Encephalitis	39	27.9%
28	Other	536	28.0%
29	Parkinson's disease	840	28.2%
30	Idiopathic intracranial hypertension	263	28.3%
31	Stroke	127	28.6%
32	RLS	278	29.1%
33	Multiple sclerosis	1189	29.6%
34	Dystonia	524	29.8%
35	Tourette syndrome	108	30.3%
36	Essential tremor	78	30.9%
37	Peripheral neuropathy	49	31.0%
38	Hydrocephalus	59	31.4%
39	Myasthenia	276	33.0%
40	I am awaiting diagnosis	591	34.8%
41	Guillain-Barré syndrome	157	37.7%
42	No primary condition	256	38.3%
43	Epilepsy	1144	43.1%

44	Acoustic neuroma	32	45.4%
45	Brain tumour	105	46.7%
46	Hemifacial spasm	41	46.8%
47	Cavernoma	88	49.6%

Fig 61. Impact of neurological condition on carrying out day to day activities

The data was then analysed by which condition causes the most significant levels of pain and discomfort (as reported by respondents within each base size). The table is again presented by condition from the respondents who reported to having the most severe pain and discomfort, to those with the least. A lower score indicates a more severe reported level of pain and discomfort.

Rank	Condition	Base	Score
1	Cluster headache	61	8.1%
2	Spinal condition	31	12.8%
3	Trigeminal neuralgia	88	13.1%
4	Migraine	720	13.6%
5	Myalgic encephalomyelitis/chronic fatigue syndrome	318	19.0%
6	RLS	277	19.3%
7	Idiopathic intracranial hypertension	263	19.6%
8	Functional neurological disorder	384	19.9%
9	Post-Polio syndrome	28	20.0%
10	Chiari malformation	40	20.7%
11	Traumatic spinal injury	30	23.2%
12	Multiple primary conditions	565	23.8%
13	Peripheral neuropathy	49	24.9%
14	Transverse myelitis	162	27.3%
15	Dystonia	526	33.2%
16	Charcot-Marie-Tooth disease	45	34.5%
17	Tourette syndrome	106	35.0%
18	Other	531	37.8%
19	Progressive supranuclear palsy	32	38.3%
20	Autoimmune encephalitis	19	38.4%
21	Traumatic brain injury	43	38.5%
22	Motor neurone disease	134	38.7%
23	Cerebral palsy	28	39.0%
24	Spina bifida	22	39.1%
25	Multiple sclerosis	1184	39.5%
26	Ataxia	181	39.5%
27	I am awaiting diagnosis	585	41.0%
28	Chronic inflammatory demyelinating polyneuropathy	68	41.3%
29	Multiple system atrophy	83	41.5%
30	Muscular dystrophy	26	42.0%
31	Parkinson's disease	839	43.9%
32	Hydrocephalus	58	43.9%
33	Acquired brain injury	103	44.3%
34	Guillain-Barré syndrome	156	45.4%
35	No primary condition	258	46.1%
36	Stroke	129	47.5%

37	Narcolepsy	96	49.6%
38	Encephalitis	41	54.9%
39	Cavernoma	88	55.7%
40	Essential tremor	77	56.0%
41	Huntington's disease	39	56.1%
42	Myasthenia	277	57.1%
43	Brain tumour	104	58.4%
44	Dementia - other (incl. frontotemporal / Lewy body / vascular)	33	59.4%
45	Acoustic neuroma	31	61.0%
46	Epilepsy	1130	63.5%
47	Hemifacial spasm	40	63.8%

Fig 62. Pain and discomfort caused by neurological condition

Finally, the data was analysed by condition on how each respondent rated the overall health care they are receiving. This table presents those who are *least* positive about their overall health care first, to those who are *most* positive at the bottom.

So, this table shows that respondents with Myalgic encephalomyelitis (ME) / chronic fatigue syndrome and those with functional neurological disorder are least satisfied with the overall health care they receive; whereas respondents with Brain tumour or Hemifacial spasm are most positive.

Rank	Condition	Base	Score
1	Myalgic encephalomyelitis/chronic fatigue syndrome	296	17.2%
2	Functional neurological disorder	348	26.8%
3	RLS	219	31.1%
4	Tourette syndrome	94	31.7%
5	Chiari malformation	35	38.8%
6	Traumatic spinal injury	26	39.5%
7	Traumatic brain injury	41	40.5%
8	Idiopathic intracranial hypertension	225	42.4%
9	I am awaiting diagnosis	335	43.3%
10	Charcot-Marie-Tooth disease	40	44.8%
11	Post-Polio syndrome	22	45.1%
12	Transverse myelitis	147	45.7%
13	Ataxia	156	47.4%
14	Multiple primary conditions	449	47.4%
15	Migraine	607	47.4%
16	Acquired brain injury	93	49.6%
17	Cerebral palsy	26	50.9%
18	Trigeminal neuralgia	74	52.4%
19	Huntington's disease	34	52.7%
20	Stroke	110	52.8%
21	Cavernoma	71	55.1%
22	Progressive supranuclear palsy	30	55.2%
23	Peripheral neuropathy	40	55.7%
24	Spinal condition	22	55.7%

25	Hydrocephalus	53	55.8%
26	Other	440	56.0%
27	Spina bifida	16	58.1%
28	Narcolepsy	86	59.0%
29	Multiple system atrophy	77	59.4%
30	Cluster headache	50	61.0%
31	Autoimmune encephalitis	19	61.1%
32	Essential tremor	56	61.1%
33	Encephalitis	33	62.5%
34	Dystonia	448	63.1%
35	Acoustic neuroma	25	63.7%
36	Epilepsy	957	63.9%
37	Multiple sclerosis	1049	65.5%
38	Dementia - other (incl. frontotemporal / Lewy body / vascular)	29	67.5%
39	Guillain-Barré syndrome	137	67.8%
40	Myasthenia	243	68.7%
41	Parkinson's disease	720	69.3%
42	No primary condition	169	70.0%
43	Motor neurone disease	128	70.8%
44	Chronic inflammatory demyelinating polyneuropathy	58	71.0%
45	Muscular dystrophy	20	71.4%
46	Brain tumour	86	71.5%
47	Hemifacial spasm	32	81.1%

Fig 63. Respondents overall ranking for health care received for their neurological condition (from least positive to most positive)

4.2 Clinic breakdown

We remain very grateful to the following neurological units who took part in this year's survey and received a response of at least 1 patient. Only those with a response of over 21 individuals were included in the analysis to protect the identity of those who took part (see suppression rules).

Hospital/clinic name	Hospital/clinic name
Bodmin Hospital	Queen Elizabeth Hospital
Cambourne and Redruth Hospital	Queen's Hospital
City Hospital	Royal Bournemouth Hospital
CRESTA	Royal Hallamshire Hospital
Cumbria Partnership & Cumbria Neurological Alliance	Royal Shrewsbury Hospital
Derby Royal Hospital	Royal Stoke University Hospital
Dorset County Hospital	Royal Victoria Infirmary
Epsom Hospital & St Helier Hospital	Salford Royal Hospital
Friarage Hospital	Southampton General Hospital
Hereford County Hospital	Southmead Hospital
Ipswich Hospital	St George's Hospital
John Radcliffe Hospital	St James Clinic
Kings College Hospital	St Mark's Hospital (Wexham Park Hospital and Frimley Park)
Leeds General Infirmary	Taunton and Somerset
Leicester General Hospital	The James Cook University Hospital
National Hospital for Neurology and Neurosurgery	The Queen Elizabeth Hospital
Norfolk and Norwich University Hospital	The Walton Centre
Penrith Hospital	University Hospital Coventry
Poole Hospital	Watford General Hospital
Princess Royal Hospital Hurstwood Park Neurological Centre	West Cornwall Hospital
Queen Alexandra Hospital	

Fig 64. Neurological units who took part in the survey

When looking at the differences between paper and online completion, those who completed the survey in clinic via a paper copy were almost universally more positive than those who completed the anonymous survey online. This was an expected finding; generally, those who are already under the expert care of a neurologist would be expected to report a more positive patient experience than those who are not. Furthermore, those who are in touch with patient organisations (who promoted the online survey) may be more likely to have more intractable forms of their neurological condition/have had worse experiences of care, leading them to seek out the expert support condition specific charities can offer.

4.3 Geography

The results show wide regional variation across the different Sustainability and Transformation Partnership (STP) areas. A full regional breakdown of scored data can be found online at https://2019survey.neural.org.uk/

4.4 Age

There were not many noticeable differences between different age groups' survey responses.

Of the noticeable differences:

- Respondents in the oldest category were more likely to be positive about their overall views of health care (this is something replicated in many other surveys).
- Respondents in the youngest age category were more likely to say their condition impacted on their ability to carry out their day to day activities.
- Older respondents were more likely to be positive about information provision.
- Older respondents were more likely to report emergency admissions as a result of their condition.

4.5 Ethnicity

As outlined at 3.1.2, for the purposes of breaking down the data, respondents who identified themselves as 'White' have been grouped together, and all those who identified themselves as Black and Minority Ethnic (BME), have been grouped together. There were not many noticeable differences between those who identified themselves as 'White' and those who identified themselves as 'BME'. It should be noted that the number of respondents identifying themselves as BME was very low (7%). Any conclusions drawn from this subset should take this into consideration and be treated with caution

Of the noticeable differences:

- BME respondents were more likely to report being given written information about their condition.
- BME respondents were more likely to be directed to further sources of information about their condition.
- BME respondents were more likely to report emergency admissions.
- BME respondents were more likely to continue with work after diagnosis.
- BME respondents were less likely to report that their financial needs are being met.
- BME respondents were more likely to be positive about their health and social care overall but less likely to report that it is meeting their needs.

4.6 Gender

More female respondents completed the survey than male respondents. As a general pattern, male respondents reported much more positive experiences than female respondents.

Of the noticeable differences:

- Male respondents were less likely to report their neurological condition causes them pain or discomfort.
- Female respondents needed to see a GP more times than male respondents before getting to see a neurologist.
- Male respondents were more likely to understand the explanation given to them at diagnosis (but were also more likely to report being given written information).
- Male respondents were far more likely to see a specialist nurse for their condition.
- Male respondents were more likely to report being seen often enough for their needs.
- Female respondents were less likely to be satisfied with the care they receive.
- Male respondents were more likely to have a care plan.
- Male respondents were more likely to continue working following diagnosis (and more likely to report having a supportive employer).
- Male respondents were less likely to report being discriminated against at work as a result of their condition.
- Female respondents were less likely to report their financial needs are being met.
- Female respondents were more likely to report problems or delays in accessing both health and social care.
- Male respondents were far more positive overall on whether health and social care is meeting their needs.

4.7 Other breakdowns

In addition to the above breakdowns, Quality Health and The Neurological Alliance cross-tabulated the data in several key areas.

Firstly, an analysis was carried out which examined how many times a respondent needed to see their GP before they were referred to a neurologist, cross-tabulated with neurological condition.

The chart below illustrates this in detail (NB a higher score is more positive). People with conditions such as Guillain-Barré syndrome, Huntington’s disease, Parkinson’s and Epilepsy see their GP fewer time before getting a referral than people with conditions such as ME, Migraine, FND and Cluster Headache.

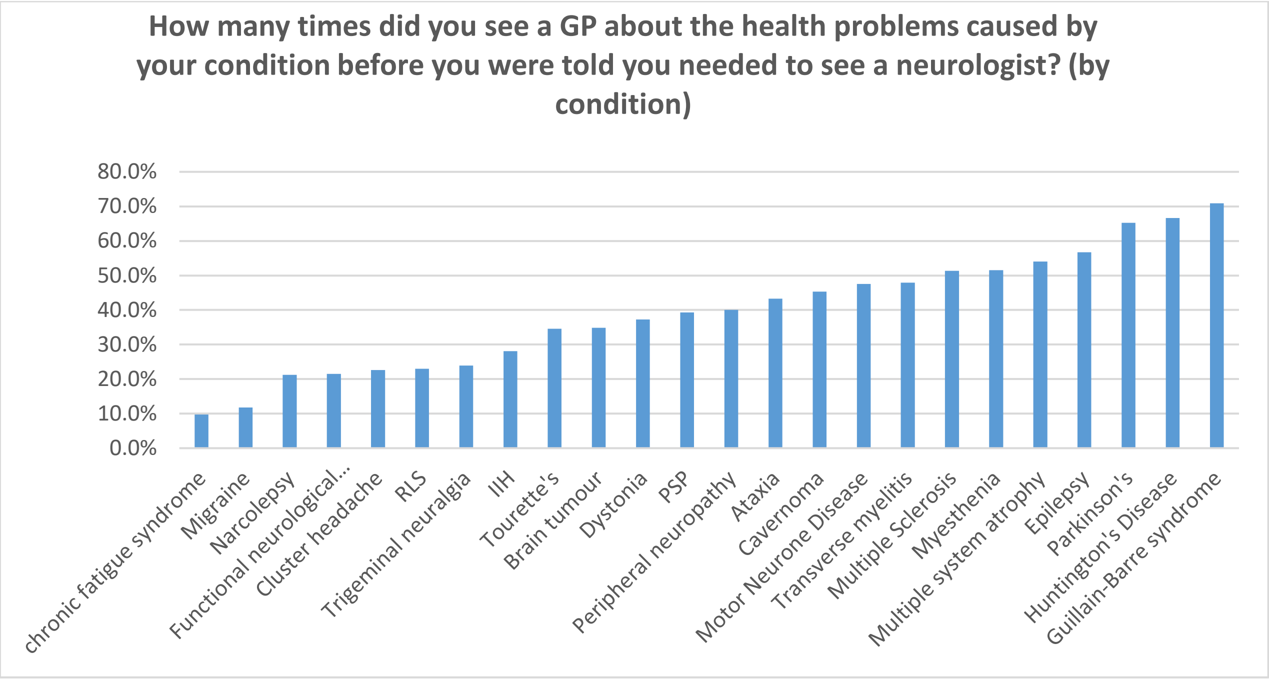


Fig 65. Wait to see a GP by neurological condition

In addition, analysis was carried out by STP (where a higher score is more positive). Respondents in Coventry and Warwickshire and in Hertfordshire were more likely to be referred to a neurologist swiftly, respondents in Northamptonshire and Devon were more likely to wait longer.

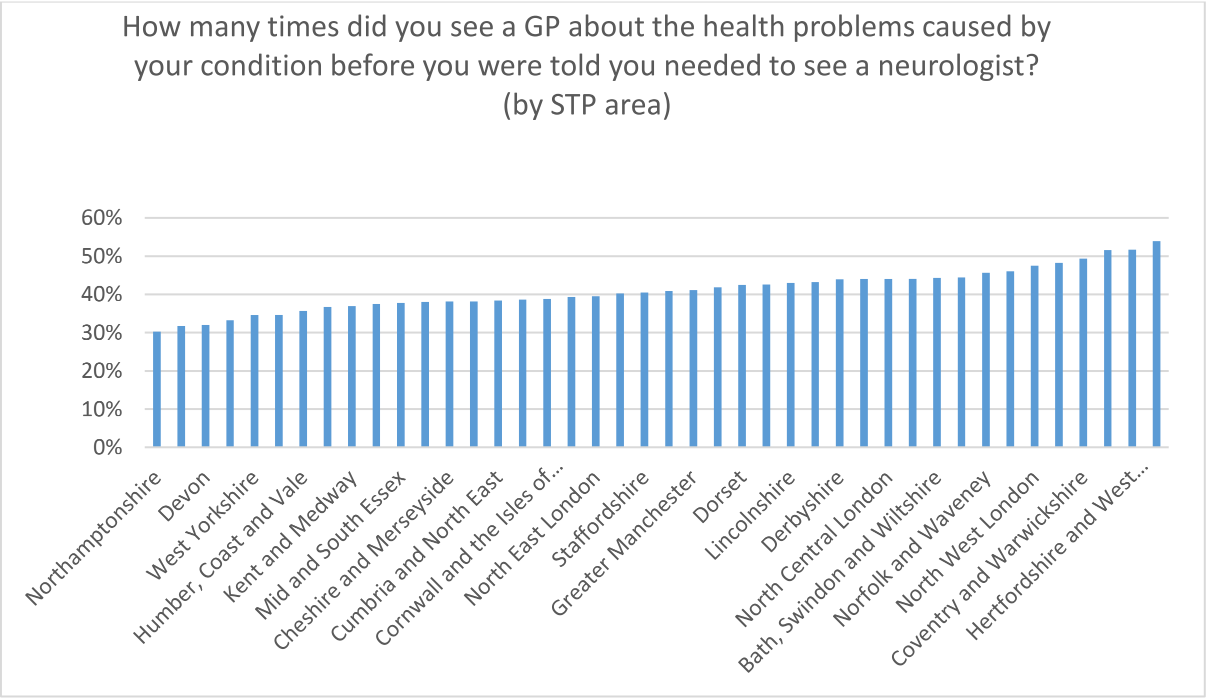


Fig 66. How many GP visits before a neurological referral, by STP

4.8 A note on further cross-tabulation of the data

The most conspicuously needed crosstabs have been presented in this report and others are presented in the *Neuro Patience* policy report. However, there are a large number of ways in which the data can be cut and analysed. This is especially true as there was a high response rate, and so multiple crosstabs could be used where more than one variable is selected. The data for the entire survey is in the process of being put onto Quality Health's online analysis tool, SOLAR, to allow for further interrogation of the data. The Neurological Alliance, and a select number of partner organisations working within neurology, will have access to this tool and be able to cut the data in any number of ways.

5. Comments and analysis

This section of the report presents a thematic analysis of the free text comments received from people with neurological conditions who returned a paper questionnaire or completed the online survey.

At the end of the survey (Q51b), respondents were invited to record any further comments that they wished to make. Every comment has been typed up by Quality Health staff, and "sanitised" (removing any patient identifiable data and removing any staff names or details). The Neurological Alliance has also been given a 'raw data' file containing all these comments.

This report presents a thematic analysis of a randomised sample of these comments.

5.1 Thematic analysis

There were 4,158 comments received in total. Due to the high number received, a thematic analysis has been carried out on a random selection of 300 comments. All comments were read in full by an analyst, and an appropriate code applied to each one.

During this process, Quality Health categorised the comments in two ways:

- By the nature of the comment, i.e., whether it is positive, negative, mixed or neutral.
- By the theme which it addresses. The themes arising from the comments are listed below in order of the highest number of comments, to lowest:

Within each of these categories, Quality Health has identified comments as positive, negative, mixed and neutral.

Many of the comments were coded more than once (for example if an individual talked about their diagnosis, ongoing treatment and employment. This means the total number of recorded comments exceeds 300. Of the 300 individual free text comments analysed, 556 individual themes were identified.

The comments were grouped as follows. The number of each comments is shown accordingly.

Theme	**Online**	**Paper**	**All**
Diagnosis	56	8	64
Treatment and Care	158	22	180
GPs	42	4	46
Information	29	3	32
Support	42	3	45
Mental Wellbeing	39	3	42
Social Care	18	2	20
Medication (prescribed)	47	1	48

Medication (non-prescribed)	5	0	5
Employment	24	2	26
Finance and Welfare	22	5	27
Other	18	3	21
TOTALS	500	56	556

Fig 67. Free text comments, by question topic

The comments were also analysed by whether they were positive or negative. The results were overwhelmingly negative (which is replicated in other major national patient surveys – but with perhaps an even higher proportion of negative comments.)

Themes	**Positive**	**Negative**	**Mixed**	**Neutral/ Suggestion**
Diagnosis	2	46	4	12
Treatment and care	27	106	39	8
GP	6	35	3	2
Information	1	28	0	3
Support	4	35	5	1
Mental wellbeing	2	38	0	2
Social care	1	14	0	5
Medication prescription	4	27	6	11
Medication non-prescription incl. substances	2	0	1	2
Employment	0	24	1	1
Patient finance and welfare	0	19	0	8
Other	1	6	0	14
Total	**50**	**378**	**59**	**69**
%	**9%**	**68%**	**11%**	**12%**

Fig 68. Free text comments, by positivity/negativity and theme

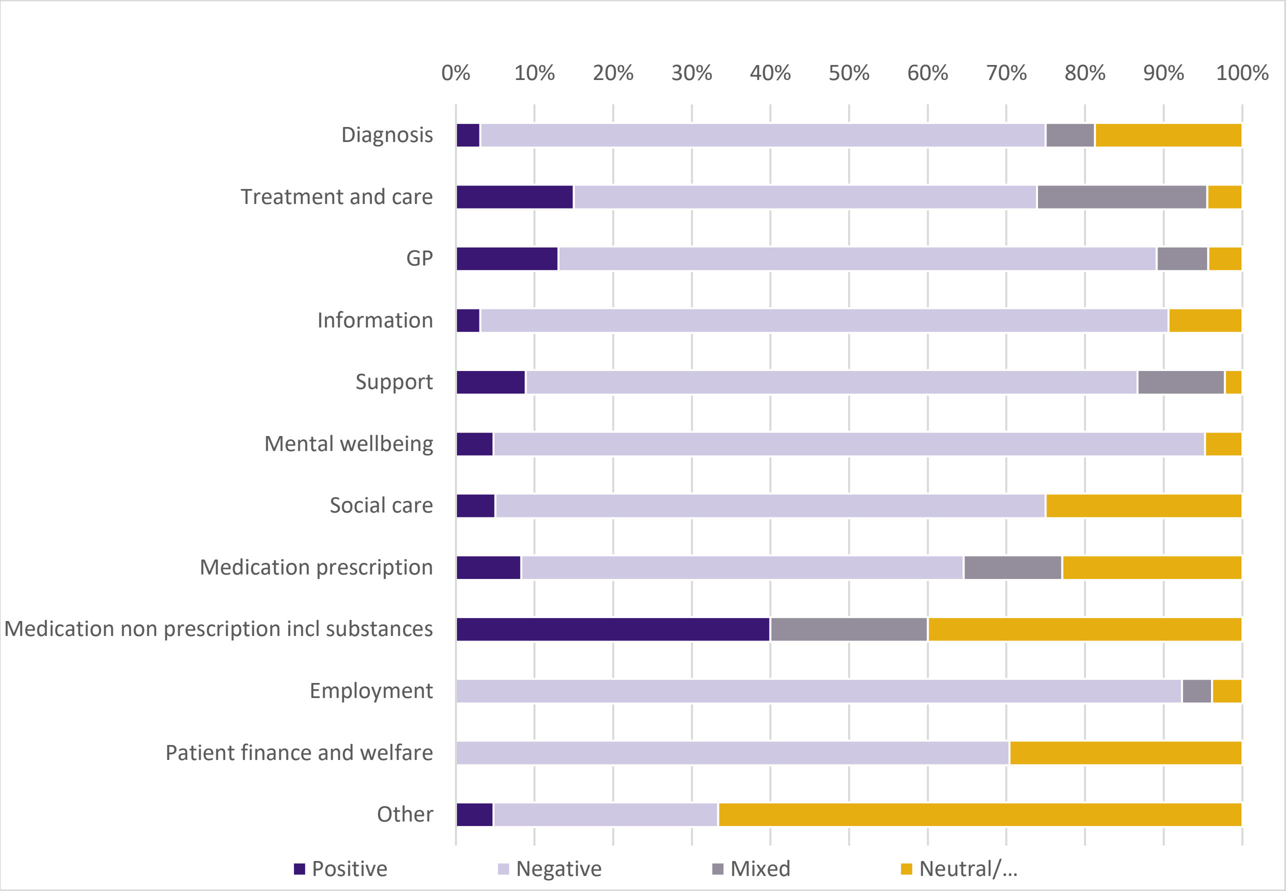


Fig 69. Free text comments by topic and tone - chart

Of interest in the chart above is that the highest proportion of positive comments related to non-prescription medication, including substances which an individual may use to help with their neurological condition.

The chart below shows the proportion of comments within each theme. Almost all comments (again in-line with other major national patient surveys) related to treatment and care.

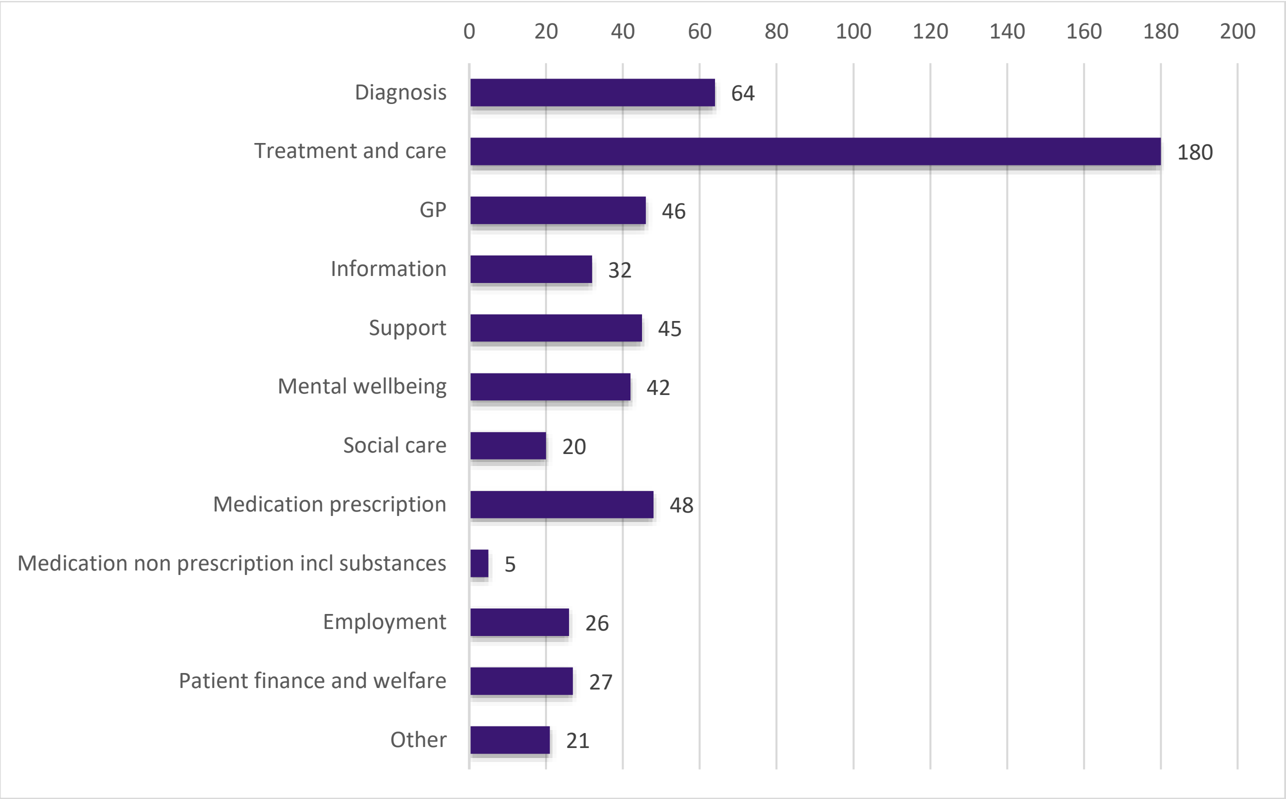


Fig 70. Proportion of free text comments within each theme

In summary:

- The majority of free text comments analysed were negative.
- The majority of free text comments analysed related to treatment and care.
- The theme with the highest proportion of positive comments related to non-prescribed medication and substances (but note very low numbers within this category).
- Themes with no positive comments related to employment and welfare.
- Mental wellbeing contained mostly negative comments.

6. Conclusions and recommendations

Conclusions and recommendations are presented in a separate policy report authored by The Neurological Alliance, which can be found at https://www.neural.org.uk/resource_library/neuro-patience

7. Next steps

This project has been an incredibly useful piece of work and it is hoped that the data, its analysis and our interpretation of it will add to data and intelligence about neurological services in England, providing the voice and views of people with neurological conditions. Moreover, it is hoped the recommendations identified will lead to improved practices for diagnosing, treating and supporting people affected by a neurological condition, which in turn will make an impact on outcomes and improved patient experience.

The survey and its findings have also identified important priorities and actions for The Neurological Alliance itself, in relation to work directly with its members (i.e. those organisations who support people with neurological conditions) and policy makers, and indirectly with patients themselves. It has also identified priorities for healthcare practitioners with whom The Neurological Alliance also works in partnership.

As well as ongoing policy and campaigns activities at national and regional level, including calling for a national neurology plan for England, The Neurological Alliance has a number of specific projects planned in the coming year using the patient experience survey data:

- Working with Getting it Right First Time (GIRFT) and The Association of British Neurologists to triangulate data about services with patient experience, in order to make recommendations about 'what works' locally and regionally in terms of neurology services.
- Defining what a 'good' neurology workforce looks like, that meets the needs of people with neurological conditions.
- Developing a project to understand and listen to the experience of people with neurological conditions from non-White British backgrounds.
- Further exploration of the experience of people with rare neurological conditions and producing a specific report with calls to action.
- Using the mental health data to lobby for neurology to be included as a priority in the focus on people with long term conditions and mental health in the long-term plan for the NHS.
- Increase our policy capacity in order to develop new policy priorities focussing on social care, welfare and employment.
- Compare and contrast the results with the forthcoming Stroke Patient Experience Survey, developed by The Stroke Association and Quality Health, with support from The Neurological Alliance.

APPENDIX A
SCORING METHODOLOGY

The table below details the scoring methodology for all scored questions within the 2018/19 Neurology survey.

In the column "Scoring key", a "1" indicates a positive answer used as part of the numerator and denominator in the scoring calculation; a decimal indicates a partially positive answer used as part of the numerator and denominator in the scoring calculation and a "0" indicates a negative answer used as part of the denominator only. A cell shaded in yellow indicates an answer not included as part of the scoring calculation.

Question		Answer option		Scoring key
Q3	To what extent does your neurological condition impact your quality of life?	1	To a great extent	0
		2	To a moderate extent	0.33
		3	To a small extent	0.66
		4	Not at all	1
		5	Don't know	🟨
Q4	To what extent does your neurological condition affect your day to day activities?	1	To a great extent	0
		2	To a moderate extent	0.33
		3	To a small extent	0.66
		4	Not at all	1
		5	Don't know	🟨
Q5	To what extent does your neurological condition cause you pain or discomfort?	1	To a great extent	0
		2	To a moderate extent	0.33
		3	To a small extent	0.66

		4	Not at all	1
		5	Don't know	

Q7	How many times did you see a GP about the health problems caused by your condition before you were told you needed to see a neurologist?	1	None – I did not see my GP before going to see a neurological specialist (includes emergency admissions)	
		2	I saw my GP once or twice	1
		3	I saw my GP three to four times	0
		4	I saw my GP five or more times	0
		5	N/A - I did not need to see a neurologist	
		6	Don't know / can't remember	

Q8	How long after first seeing your GP was it before you saw a neurologist?	1	Not applicable / I did not need to see a neurologist	
		2	I did not see a GP before I saw a neurologist (this includes emergency admissions)	
		3	Less than 3 months	1
		4	3-6 months	0.66
		5	7-12 months	0.33
		6	More than 12 months	0
		7	Don't know / can't remember	

Q11	Did you/your family understand the explanation given to you at your diagnosis / when you were first told about your condition?	1	Yes, I/we completely understood it	1
		2	Yes, I/we understood some of it	0.5
		3	No, I/we did not understand it	0
		4	I/we were not given an explanation	
		5	Don't know / can't remember	

Q12[1]	When you were told you had a neurological condition, were you given written information about this?	-	Yes, I was given the hospital's own written information	1
		-	Yes, I was given written information from a specific charity	1
		-	Yes, I was given the hospital's own written information and written information from a specific charity	1
		-	I was not offered written information	0

		-	I did not need written information	
		-	Don't know / can't remember	
		-	Other	

Q13	How would you rate the quality of this information?	1	Excellent	1
		2	Good	0.66
		3	Fair	0.33
		4	Poor	0
		5	Don't know	
		6	N/A	

Q14	What did the health professional who gave you your diagnosis say about finding further information?	1	I was told to contact the hospital	1
		2	I was told to contact a specific charity	1
		3	I was told to look at a specific website on the internet	1
		4	I was told to look at the internet, but no website was specified	0
		5	I was not told anything about finding further information	0
		6	Don't know / can't remember	

Q19	Do you see a specialist nurse for your neurological condition?	1	Yes	1
		2	No, but I would have liked this	0
		3	No, but I do not want / need this	
		4	Don't know	

Q26	How many times have you had an emergency admission to hospital (i.e. an unscheduled stay in hospital) as a result of your neurological condition in the past two years?	1	Never	1
		2	1-2 times	0
		3	3-5 times	0
		4	6-9 times	0
		5	10 or more times	0
		6	Don't know / can't remember	

Q28a	...I am seen often enough for my needs.	1	Agree	1
		2	Neither agree nor disagree	0
		3	Disagree	0
		4	Not applicable	

Q28b	...I am satisfied with the care I receive.	1	Agree	1
		2	Neither agree nor disagree	0
		3	Disagree	0
		4	Not applicable	

Q28c	...Information about my specialist treatment and my condition is effectively passed on to the people that care for me (such as my GP, nurse, or family carer).	1	Agree	1
		2	Neither agree nor disagree	0
		3	Disagree	0
		4	Not applicable	

Q28d	...I got the care I needed at home after my hospital visit.	1	Agree	1
		2	Neither agree nor disagree	0
		3	Disagree	0
		4	Not applicable	

Q29[1]	Have you been offered a care plan to help manage your neurological condition?	-	Yes, by my health care team	1
		-	Yes, by my social care team	1
		-	Yes, by my health care team and by my social care team	1
		-	No, but I would like one	0
		-	I don't need a care plan	
		-	I don't know what a care plan is	
		-	Don't know / can't remember	

Q31	Have you been asked about your mental wellbeing by a health or social care professional?	1	Yes	1
		2	No	0
		3	Don't know / can't remember	

Q35	To what extent do you feel your mental wellbeing needs are being met?	1	To a great extent	1
		2	To a moderate extent	0.66
		3	To a small extent	0.33
		4	Not at all	0
		5	Don't know	
		6	N/A	

Q39	To what extent do you feel your care and support needs are being met?	1	To a great extent	1
		2	To a moderate extent	0.66
		3	To a small extent	0.33
		4	Not at all	0
		5	Don't know	

Q43a	I have been able to continue work as normal since my neurological condition was diagnosed.	1	Agree	1
		2	Neither agree nor disagree	0
		3	Disagree	0
		4	Not applicable	

Q43b	My employer has supported me through my diagnosis and treatment.	1	Agree	1
		2	Neither agree nor disagree	0
		3	Disagree	0
		4	Not applicable	

Q43d	I have missed out on opportunities to develop my career due to my neurological condition.	1	Agree	0
		2	Neither agree nor disagree	0

		3	Disagree	1
		4	Not applicable	

Q43f	I can no longer carry out my job due to the effects of my neurological condition.	1	Agree	0
		2	Neither agree nor disagree	0
		3	Disagree	1
		4	Not applicable	

Q43g	I have been discriminated against due to my neurological condition.	1	Agree	0
		2	Neither agree nor disagree	0
		3	Disagree	1
		4	Not applicable	

Q43h	My contract of employment has been terminated due to my neurological condition.	1	Agree	0
		2	Neither agree nor disagree	0
		3	Disagree	1
		4	Not applicable	

Q45	Do you feel your financial needs are being met?	1	Yes	1
		2	No	0
		3	Don't know / prefer not to say	

Q46a	Do you feel fully involved in making choices about your health and social care? Social Care	1	Yes, definitely	1
		2	Yes, to some extent	0.5
		3	Not really	0
		4	Not at all	0
		5	Don't know / N/A	

Q46b	Do you feel fully involved in making choices about your health and social care? Health Care	1	Yes, definitely	1
		2	Yes, to some extent	0.5
		3	Not really	0
		4	Not at all	0
		5	Don't know / N/A	

Q47a	Have you experienced any problems or delays in accessing health care services or social care services to help manage your condition? Social Care	1	Yes	0
		2	No	1
		3	Don't know / N/A	

Q47b	Have you experienced any problems or delays in accessing health care services or social care services to help manage your condition? Health Care	1	Yes	0
		2	No	1
		3	Don't know / N/A	

Q48a	Overall, how do you rate the care and treatment you have received for your condition? Social Care	1	Very good	1
		2	Good	0.66
		3	Fair	0.33
		4	Poor	0
		5	Don't know / N/A	

Q48b	Overall, how do you rate the care and treatment you have received for your condition? Health Care	1	Very good	1
		2	Good	0.66
		3	Fair	0.33
		4	Poor	0
		5	Don't know / N/A	

Q49a	Please indicate how much you agree with the following statements: Overall, the health care I have received meets my needs.	1	Agree	1
		2	Neither agree nor disagree	0
		3	Disagree	0

		4	Not applicable	

Q49b	Please indicate how much you agree with the following statements: Overall, the social care I have received meets my needs.	1	Agree	1
		2	Neither agree nor disagree	0
		3	Disagree	0
		4	Not applicable	

Fig 71. Scoring methodology

Questions 12 and 29 are both structured as Tick All That Apply questions that require special scoring conditions. For both questions, response options 1 and 2 are scored with a ‘1’ if answered independently. If both are ticked, additional data cleansing has been applied to create a new response option.

This was done to ensure that the respondent isn’t counted twice in the report. The following statements explain the method used to cleanse the data:

- If response option 1 has been ticked and response option 2 has NOT been ticked, then no data cleansing is applied.
- If response option 2 has been ticked and response option 1 has NOT been ticked, then no data cleansing is applied.
- If both response options 1 and 2 have been ticked, the new response option is completed. The original responses are removed from the data to ensure that respondent is not counted twice.

APPENDIX B
ANALYSIS OF CONDITION SPECIFIC DATA BY NATIONAL NEUROLOGICAL PREVALANCE DATA

Weightable Conditions	Prevalence	Prevalence %	Data Count	Data %	Weighting Factor	Weighted Counts
Acquired brain injury/Traumatic brain injury	1,095,152	6.71%	148	2.38%	2.82	417
Autism	580,000	3.55%	10	0.16%	22.08	221
Brain tumour	85,927	0.53%	109	1.75%	0.30	33
Cavernoma	90,000	0.55%	90	1.45%	0.38	34
Cerebral palsy	25,273	0.15%	28	0.45%	0.34	10
Cluster headache	111,200	0.68%	62	1.00%	0.68	42
Congenital hemiplegia	55,600	0.34%	4	0.06%	5.29	21
Dementia (includes Alzheimer's)	759,000	4.65%	51	0.82%	5.67	289
Dystonia	58,970	0.36%	530	8.53%	0.04	22
Epilepsy	526,000	3.22%	1,157	18.62%	0.17	200
Essential tremor	842,424	5.16%	78	1.26%	4.11	321
Fibromyalgia	1,167,600	7.15%	13	0.21%	34.19	445
Migraine	7,945,633	48.68%	726	11.68%	4.17	3025
Motor neurone disease	3,962	0.02%	137	2.20%	0.01	2
Multiple sclerosis	90,590	0.56%	1,195	19.23%	0.03	34
Muscular dystrophy	58,970	0.36%	26	0.42%	0.86	22
Myalgic encephalomyelitis/chronic fatigue syndrome	210,606	1.29%	319	5.13%	0.25	80
Parkinson's disease	121,927	0.75%	847	13.63%	0.05	46
Post-Polio syndrome	100,800	0.62%	28	0.45%	1.37	38
RLS	1,056,400	6.47%	280	4.51%	1.44	402
Stroke/transient ischaemic attack	1,000,000	6.13%	150	2.41%	2.54	381
Tourette syndrome	252,000	1.54%	108	1.74%	0.89	96
Traumatic spinal injury	34,303	0.21%	30	0.48%	0.44	13
Trigeminal neuralgia	50,000	0.31%	88	1.42%	0.22	19

Total Weightable	**16,322,337**	**6,214**		**6,214**

Unweightable Conditions	**Prevalence**	**Data Count**	**Weighting Factor**	**Weighted Counts**
No prevalence data	0	853	1.00	853
No responses	150,621	0	1.00	0
I am awaiting diagnosis	0	640	1.00	640
Rarer Conditions	0	1,434	1.00	1434
Other	0	329	1.00	329
Multiple primary conditions	0	578	1.00	578
No Primary Condition	0	291	1.00	291
Total Unweightable	**150,621**	**4,125**		**4,125**
Overall	**16,472,958**	**10,339**		**10,339**

Fig 72. Prevalence analysis and consideration of weighting

Taking this information into account, the data was presented as unweighted results with an acknowledgement there are different levels of representation and engagement amongst certain groups of conditions. If the weighting factors were applied, the assumption would be that the small number of responses received for underrepresented conditions are representative of the overall condition populations – an assumption which is likely to be incorrect in many instances. For example, it would seem unreasonable to assume that the opinions of the 13 respondents for Fibromyalgia are representative of the 1.2m individuals known to have this condition.

APPENDIX C

TOTAL CONDITION COUNTS OVERALL

Condition	Total Count
Acoustic neuroma	44
Acquired brain injury	190
Acromegaly	1
Acute disseminated encephalomyelitis	1
Antiphospholipid syndrome	1
Arachnoiditis	8
Arteriovenous malformation	10
Ataxia	271
Autism	12
Autoimmune encephalitis	29
Batten disease	1
Bell's palsy	3
Blepharospasm	14
Brain abscess	1
Brain aneurysm	6
Brain cyst	19
Brain tumour	178
Brown-Sequard syndrome	1
Camptocormia	1
Carpal tunnel syndrome	179
Cauda equina syndrome	3
Cavernoma	122
Cerebral palsy	54
Charcot-Marie-Tooth disease	50
Chiari malformation	40
Chronic idiopathic axonal polyneuropathy	1
Chronic inflammatory demyelinating polyneuropathy	79
CLIPPERS syndrome	1
Cluster headache	223
CNS inflammation	1
Complex regional pain syndrome	6
Compression neuropathy	1
Congenital hemiplegia	11
Congenital insensitivity to pain with anhidrosis	1
Corticobasal degeneration	6
CSF leak	2
Dementia - Alzheimer's	31
Dementia - frontotemporal	9
Dementia - Lewy body	17
Dementia - other	27
Dementia - other (incl. frontotemporal / Lewy body / vascular)	33
Dementia - vascular	14
Dercum’s disease	1
Dural arteriovenous fistula	1
Dysautonomia	1
Dystonia	642
Encephalitis	63

Encephalopathy	1
Epilepsy	1480
Essential tremor	178
Familial amyloid polyneuropathy	1
Fibromyalgia	13
Filamin A mutation	1
Foot drop	1
Fowler's syndrome	2
Functional neurological disorder	512
Global developmental delay	1
Glucose transporter deficiency syndrome	1
Granulomatosis	1
Grierson Gopalan syndrome	1
Guillain-Barré syndrome	173
Haemorrhagic leukoencephalitis	1
Hemifacial spasm	41
Hereditary neuropathy with pressure palsies	1
Hereditary spastic paraplegia	14
Huntington's disease	43
Hydrocephalus	107
Hypokalemic periodic paralysis	1
I am awaiting diagnosis	816
Idiopathic hypertrophic pachymeningitis	1
Idiopathic intracranial hypertension	302
Immune-mediated neuropsychiatric disorder	1
Internal carotid artery dissection	1
Kennedy’s disease/SBMA	6
Kernicterus	1
Leptomeningeal thickening	1
Leukoencephalopathy	1

Limb-kinetic apraxia	1
Lipid myopathy	1
Lumbar spinal stenosis	1
Lyme disease	3
Madsam neuropathy	2
Mal de debarquement syndrome	9
Malignant neuroleptic syndrome	0
McArdle's disease	2
Meares-Irlen syndrome	1
Meniere's disease	1
Meningitis	35
Methylmalonic acidemia	1
Migraine	1469
Mitochondrial disease	6
Motor neurone disease	147
Motor neuropathy	1
Moyamoya disease	1
Multifocal motor neuropathy	2
Multiple sclerosis	1245
Multiple system atrophy	92
Multiple-acyl-CoA dehydrogenase deficiency	1
Muscular dystrophy	33
Muscular neuropathy	1
Myalgic encephalomyelitis/chronic fatigue syndrome	488
Myasthenia	298
Myelomalacia	1
Myelopathy	39
Myoclonus	1
Myopathy	1
Myositis	13

Myotonic disorders	15
Narcolepsy	118
Necro surgery on neck	1
Nerve damage	10
Neuro-Behçet's disease	2
Neurodegeneration with brain iron accumulation	4
Neurofibromatosis	20
Neuromyelitis optica	20
Neuropathic pain	1
Neuropathy	20
Olfactory groove meningioma	1
Other	0
Pachygyria	1
PANDAS	5
Parkinson's disease	909
Paroxysmal hemicrania	1
Peripheral neuropathy	49
Pernicious anaemia	20
Petrous apecitis	1
Pituitary lesion	1
POEMS syndrome	1
Poliomyelitis	27
Polymicrogyria	2
Post-Polio syndrome	42
POTS	8
Primary lateral sclerosis	1
Progressive supranuclear palsy	36
Pure autonomic failure	2
Radiation-induced lumbar plexopathy	4
Radiculopathy	30

Radiologically isolated syndrome	1
Refsum's disease	2
Retinal atrophy	1
Rett syndrome	1
RLS	490
Sarcoidosis	8
Scoliosis	1
Sensory ganglionopathy	1
Sensory neuropathy	1
Sjögren's syndrome	1
Skull base chordoma	1
Sleep disorder	2
Somatoform disorders	7
Spina bifida	48
Spinal condition	31
Spinal muscular atrophy	21
Spinal stenosis	1
Spinal tumour	30
Spinocerebellar atrophy with genetic mutation	1
Spondylosis	131
Stiff person syndrome	5
Stroke	237
Stroke/transient ischaemic attack	107
Susac syndrome	1
Syncope	2
Syringomyelia	3
Tardive dyskinesia	1
Thrombosis	4
Torticollis	4
Tourette syndrome	128

Transient global amnesia	3
Transverse myelitis	188
Traumatic brain injury	80
Traumatic spinal injury	55
Trigeminal autonomic cephalalgia of hemicranial subtype	1
Trigeminal neuralgia	183
Tuberous sclerosis	6
Vasculitis	4
Vertigo	6
Vestibular schwannoma	1
Other neurological condition	1185
TOTAL	14346

Fig 73. Total condition counts overall