



**November - December 2023 Summary Insights**  
**The impact of neurological conditions on mental health & access to  
specialists' appointments**

Brain & Spine  
Foundation

THE  
NEUROLOGICAL  
ALLIANCE

COMMUNITY  
FUND

## **About NeuroLifeNow**

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

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

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

## Foreword

The final survey of 2023 for NeuroLifeNow was our most successful yet, thanks to the overwhelming participation of our growing community. More than 600 people responded, representing over 100 different neurological conditions. This level of engagement underscores the importance of the work we're doing and provides a strong foundation for amplifying the voices of those living with neurological conditions.

### The Power of Community

The NeuroLifeNow community continues to grow, and with that growth comes increased strength and influence. By sharing your experiences, you're helping to shape a future where people with neurological conditions have a louder, more unified voice. This is crucial in advocating for better healthcare services, improved policies, and greater public awareness. As we look ahead, your participation enables us to draw clearer insights from the data and speak with even greater authority about the challenges and needs of those with neurological conditions.

### Complex Health Challenges

One of the most striking findings from the survey was the complexity many people face in managing their health. Nearly half of the respondents (48%) reported having more than one neurological condition, and 71% said they had an additional non-neurological condition. This means that a significant number of people are juggling multiple health concerns, which can complicate their healthcare journeys. The healthcare system often struggles to meet the needs of these individuals, indicating a gap that must be addressed.

### Positive Healthcare Experiences

Despite these challenges, there are reasons for optimism. Four in 10 respondents (41%) reported a positive experience with health and care services, and more than seven in 10 (72%) found their health appointments helpful. This shows that when people can access healthcare, they often find it beneficial. However, those with multiple neurological conditions were less likely to have a positive experience, suggesting that the healthcare system might not be adequately equipped to handle complex cases. This is an area where improvement is needed.

## **Bridging the Gap**

The fact that so many people found their health appointments helpful is encouraging. It indicates that healthcare providers are making a positive impact, even if there's still room for improvement. Our goal at NeuroLifeNow is to ensure that these positive experiences become universal, regardless of where people live or how complex their health needs are. By focusing on the core questions that matter to you, we aim to improve your experience with our platform and, by extension, contribute to the broader effort to enhance healthcare services for people with neurological conditions.

## **Thank You**

Your experiences have been used to inform neurology transformation programmes nationally, influence major Government health initiatives and influence healthcare practice.

As we close out 2023, we want to express our deepest gratitude to the thousands of people who have taken the time to respond to NeuroLifeNow this past year. Your insights and stories are invaluable in helping us understand the realities of living with neurological conditions. Together, we're building a community that can drive meaningful change and make a real difference in the lives of those affected by neurological conditions.

Thank you for your support, and we look forward to continuing this journey with you in the coming year.

**Marc Smith, CEO Brain and Spine Foundation**

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

## Key Findings

**672** responses were received in November to December 2023. **114 conditions were represented**, and 48% reported living with more than one condition.

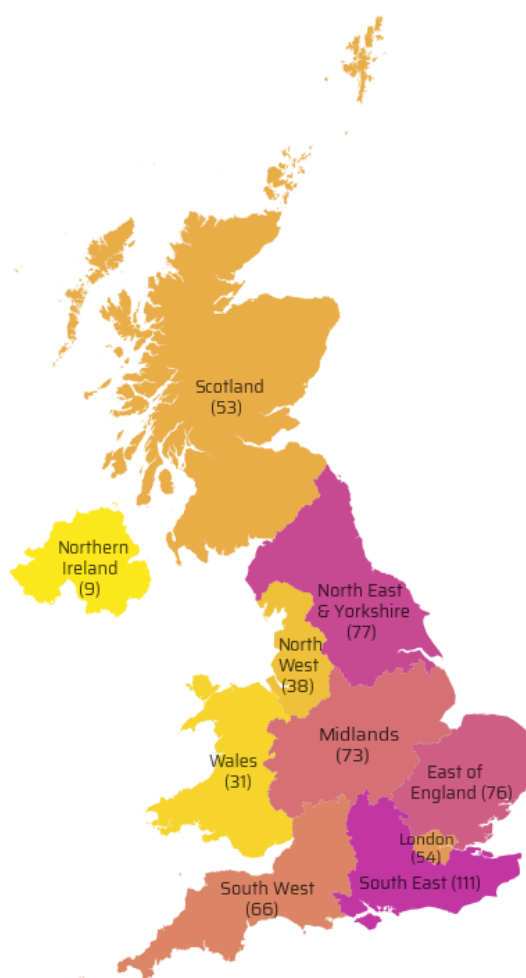


Figure 1: Location of the respondents.

**41% of respondents had good or very good experience of health and care** in November and December 2023. **People reporting multiple conditions were less likely to say that their overall experience of healthcare was good or very good**, compared to those with one condition.

**71% of people reported living with a (non-neurological) condition** in addition to their neurological condition.

**More than half (52%) of respondents said they were feeling anxious.** Just 18% said they felt well supported.

| Feelings              | Respondents | Percentage |
|-----------------------|-------------|------------|
| <b>Anxious</b>        | 352         | 52.38      |
| <b>Hopeless</b>       | 202         | 30.06      |
| <b>Lonely</b>         | 183         | 27.23      |
| <b>Calm</b>           | 159         | 23.66      |
| <b>Well supported</b> | 122         | 18.15      |

Table 1: Feelings of the respondents at the time of the survey.

**37% of people said their mental health needs were not being met at all.** People living with multiple neurological conditions were more likely to report this.

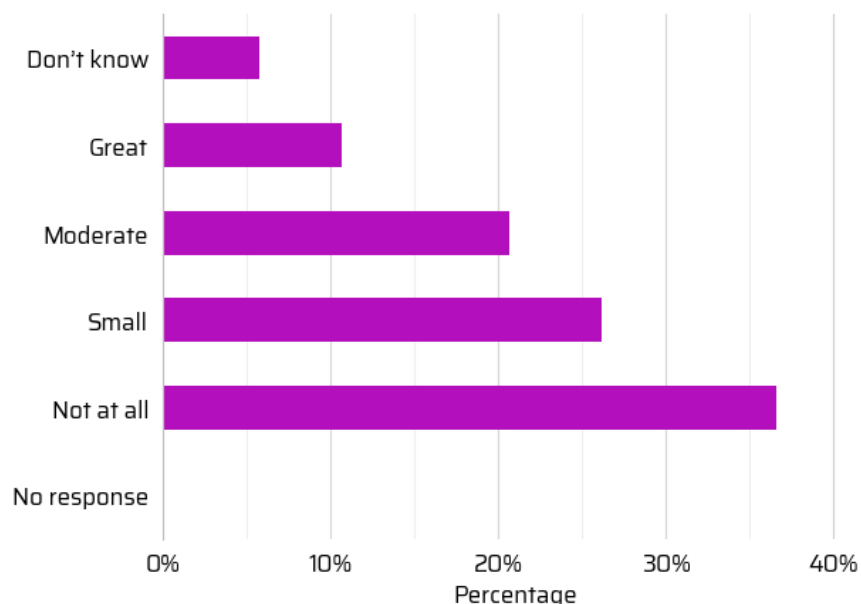


Figure 2: The extent to which respondents' mental health needs were met.

**64% of people had a healthcare appointment in the past 8 weeks.** 7% had more than 5 appointments in just 8 weeks.

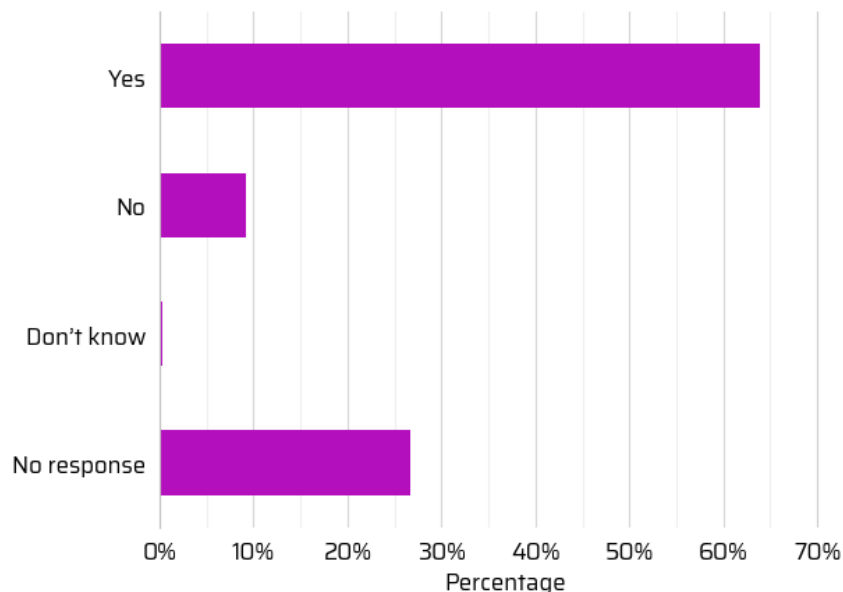


Figure 3: Access to medical appointments in the last eight weeks.

**72% found their appointments helpful.** A third (33%) of appointments were held with a GP, 21% with a specialist nurse.

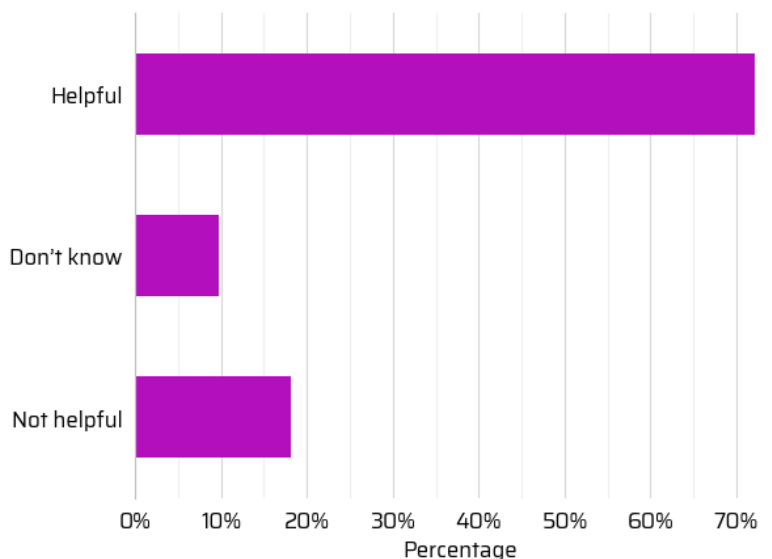


Figure 4: Helpfulness of medical appointments held in the last eight weeks.

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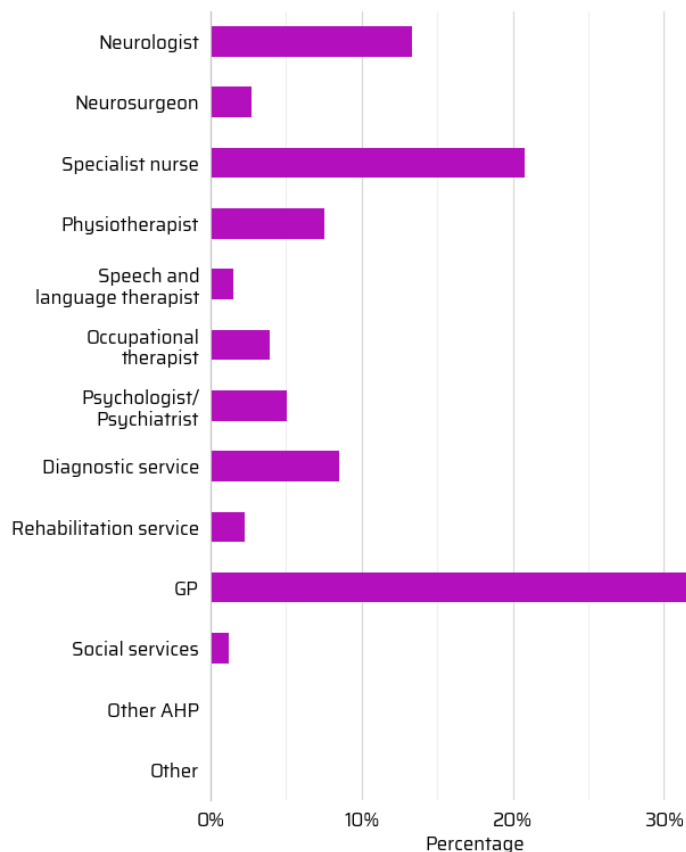


Figure 5: Speciality of the medical appointments held in the last eight weeks.

The **majority (78%) of appointments** were held **face to face**.

| Mode             | Respondents | Percentage |
|------------------|-------------|------------|
| Phone            | 193         | 18.56      |
| Video conference | 31          | 2.98       |
| Text/WhatsApp    | 10          | 0.96       |
| Face to face     | 806         | 77.5       |
| Other            | 0           | 0.0        |
| None of these    | 0           | 0.0        |

Table 2: Mode of medical appointments completed in the last eight weeks.



**This is a summary of the full report. To view our full report, click [here](#).**