



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



About NeuroLifeNow

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

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

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

Foreword

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

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

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

Too many people are experiencing long waits

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

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

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

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

Specialist care too far

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

Care should be delivered as close to home as possible. Specialist input should be available in every region of the country, but is often out of reach. Many people shared with us this month

the agonizing journey they have to undertake to see their specialist, often at great personal cost.

Turning to private health care

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

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

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

Not everyone experiences poor care

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

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

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

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

Thank you

The Brain & Spine Foundation Team

Georgina Carr, CEO, The Neurological Alliance, England

Key Findings

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

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

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

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

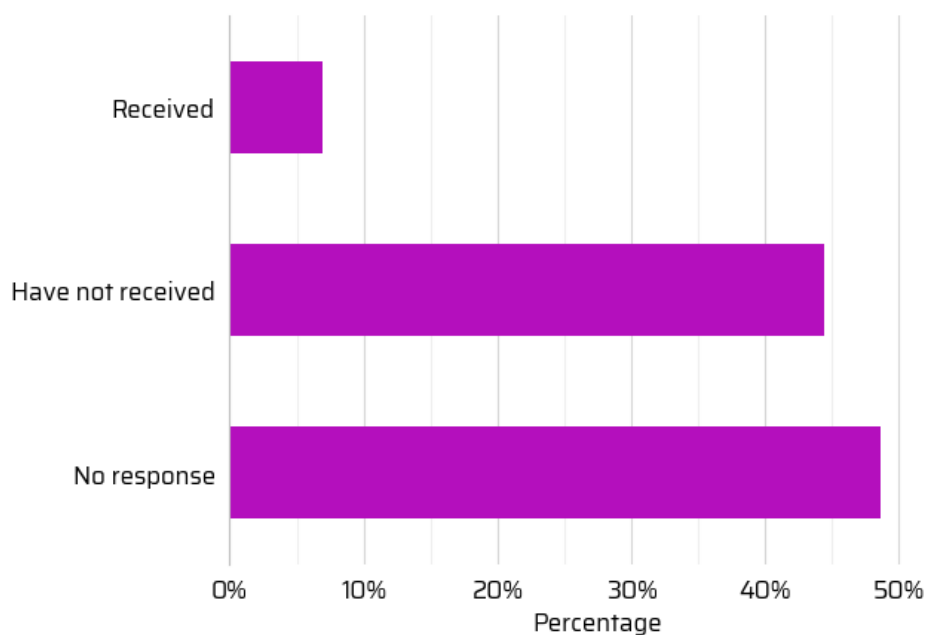


Figure 1 Whether received information from the NHS on available support while waiting

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

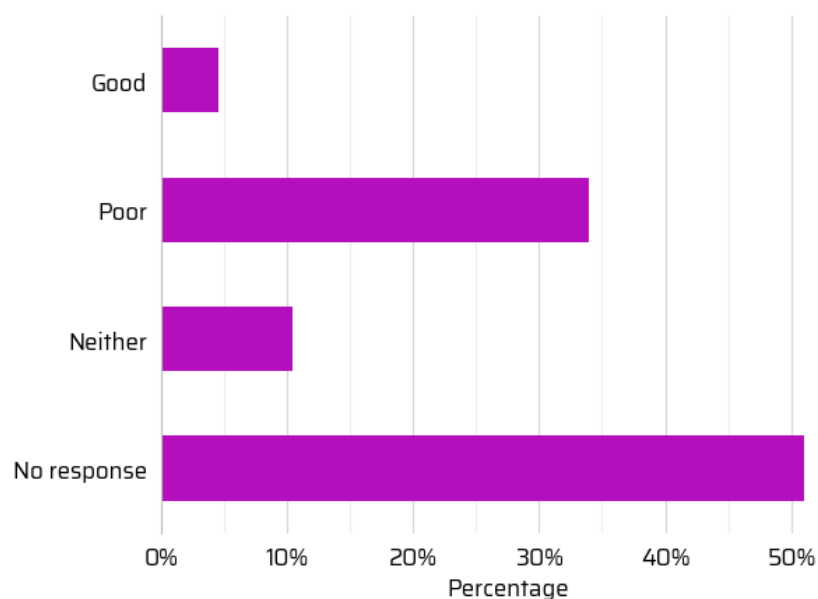


Figure 2 Quality of communications from the NHS while waiting

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

Table 1 Overall experience of healthcare

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

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

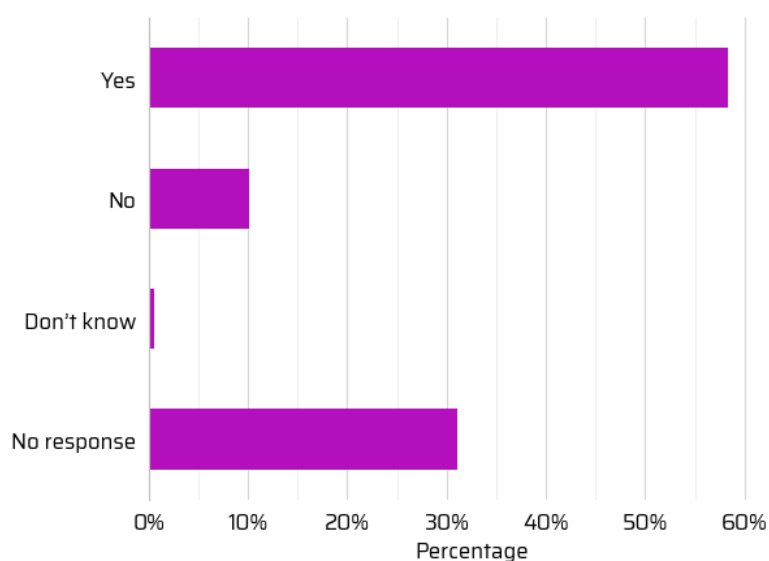


Figure 3 Access to medical appointments in the last eight weeks

Table 3 Specialty of the medical appointments held in the last eight weeks

Specialty	Respondents	Percentage
Neurologist	156	13.03
Neurosurgeon	28	2.34
Specialist nurse	199	16.62
Physiotherapist	124	10.36
Speech and language therapist	17	1.42
Occupational therapist	23	1.92
Psychologist/ Psychiatrist	52	4.34
Diagnostic service	106	8.86

Rehabilitation service	23	1.92
GP	461	38.51
Social services	8	0.67
Other AHP	0	0.0
Other	0	0.0

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

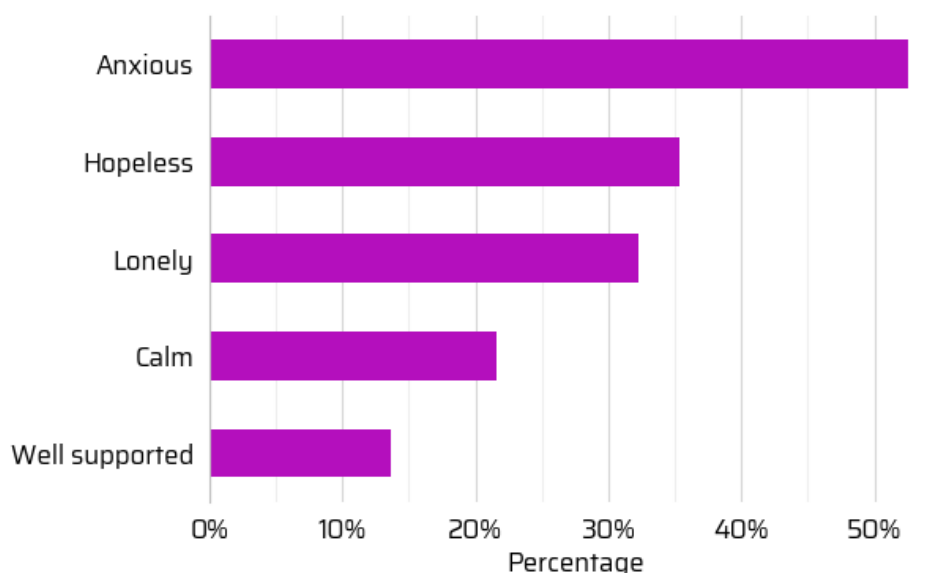


Figure 4 Feelings of the respondents at the time of the survey

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