The National Neurology Patient Experience Survey presents a comprehensive picture of the experiences of people living with a neurological condition in England. The survey has been run biennially by The Neurological Alliance since 2014.

Covering three main themes – accessible, personalised and holistic care and support (which includes social care, mental health and financial security) – the 2018/19 results show that people’s experiences remain poor. This year the results are also broken down to regional level. Our online interactive map shows the patient experience survey scores for each Sustainability and Transformation Partnership footprint, revealing wide regional variation in the experience of people with neurological conditions. The full Neuro Patience report and interactive map can be found on our website.

To download the full report visit www.neural.org.uk/patient-experience-survey

Accessible

39% of respondents saw their GP five or more times before being told they needed to see a neurologist*

29% of respondents who needed to see a neurologist waited more than 12 months

55% of respondents said they have experienced delays in accessing health care

38% of respondents do not have access to a specialist nurse but would like this support

30% of respondents have not been referred or signposted to mental health support but would like this**

34% of respondents do not believe they see a specialist often enough to meet their needs

* Of those who said they saw a GP
** Of those who said they have mental health needs
Neuro Patience: The National Neurology Patient Experience Survey 2018/19

Recommendations

Care and support for people with neurological conditions must be:

ACCESSIBLE
1 A national neurology plan for England should be urgently developed to address delays in the system and regional variation in access to services.

2 Sustainability and Transformation Partnerships/Integrated Care Systems should include neurology as a priority area for improvement in their plans; especially in areas where patient experience is consistently lower than the national average.

PERSONALISED
3 Person centred care should be provided to all people with neurological conditions through delivering the commitment to personalised care contained in the Long Term Plan for the NHS, especially in relation to information provision at the time of diagnosis and care planning.

HOLISTIC
4 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
   b Redoubling efforts to tackle structural and institutional barriers to employment
   c Reform to the welfare system in line with the Disability Benefits Consortium’s calls

5 Neurology should be prioritised for mental health improvement initiatives aimed at people with long term conditions such as the commitments made in the Long Term Plan for the NHS.

Survey methodology

The full survey roll-out took place in select neurology clinics and online, from July 2018 to March 2019. It received 10,339 responses. The full survey findings and methodology, along with the stories behind the data, can be read at www.neural.org.uk/patient-experience-survey

10,339
Number of people who responded to our survey

www.neural.org.uk/patient-experience-survey

Personalised

PROVISION OF INFORMATION
43% of respondents were not given written information when they were told they had a neurological condition

COMMUNICATION
23% of respondents were not given an explanation of their diagnosis, that they understood, when they were first told they had a neurological condition

SHARED DECISION MAKING
30% of respondents do not feel involved in making choices about their healthcare

CARE PLANNING
10% of respondents have been offered a care plan

COORDINATED
28% of respondents disagree that information about their treatment and condition is effectively passed between the different people who care for them

Holistic

% of respondents reporting their needs are not being met at all, in relation to:

40% Mental health
43% Financial
38% Social care
26% Health care

40% 43% 38% 26%