

# NEURO PATIENCE

## The National Neurology Patient Experience Survey 2018/19

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.

### The Neurological Alliance

The Neurological Alliance is a coalition of 80 organisations working together to transform outcomes for the millions of people in England with a neurological condition. We campaign for high quality care and support to meet the individual needs of every person with a neurological condition, at every stage of their life.

For more information about the survey or for a discussion about the findings please get in touch [info@neural.org.uk](mailto:info@neural.org.uk) or 01923 882 590.

### Contact us

The Neurological Alliance  
c.o. The British Polio Fellowship  
The Xchange Building  
Wilmington Close  
Watford  
Hertfordshire  
WD18 0FQ

**Email:** [info@neural.org.uk](mailto:info@neural.org.uk)  
**Phone:** 01923 882 590

The Neurological Alliance is a charity registered by the Charity Commission for England and Wales (registration number 1039034) and a company limited by guarantee registered in England (registration number 2939840).

### 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

## 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:



## 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.

### 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

### 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.

- 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](http://www.neural.org.uk/patient-experience-survey)

