



THE
**NEUROLOGICAL
ALLIANCE**

Supporting #MyNeuroSurvey

Getting the right neurology treatment, care and support at the right time matters.

We know that getting the right care, treatment and support at the right time can make a lifechanging difference when you have a neurological condition.

But there are huge levels of variation in neurology service provision across the UK and not everyone with a neurological condition has access to the same high quality, joined up care.

Making the case for change is a huge challenge.

That's why we need your help – we're asking all Alliance members to do 3 things to support My Neuro Survey:

1. **NOW** – email miranda.lloyd@neural.org.uk to register your interest in supporting My Neuro Survey and receive a campaign pack including a unique link to the survey and resources to help you promote the survey online, in print and through social media.
2. **NOW** – let us know why you're supporting My Neuro Survey. This will help us promote the survey and show why it is so important when it comes to making the case for change.
3. **FROM 25th October – 14th January** – share, promote and shout about My Neuro Survey.

Neurology services are more stretched than ever – your support is more important than ever.

We're delighted that for the first time My Neuro Survey is UK wide and includes a version specifically for children and young people with neurological conditions.

When you register your interest in supporting the survey, we will send you a campaign pack with a unique link to the survey and resources to help you promote the survey online, in print and through social media.

The survey will open online on 25th October 2021 and close on 14th January 2022.

It takes around 20 minutes to complete.



What is #MyNeuroSurvey?

My Neuro Survey is the largest patient experience survey of people with neurological conditions.

My Neuro Survey is the biggest single source of patient experience data when it comes to commissioning services for people with neurological conditions and lobbying to improve treatment, care and support for people with neurological conditions.

The Neurological Alliance runs the National Neurological Patient Experience Survey (now called 'My Neuro Survey') every two years.

“In the absence of robust data from the NHS about the provision of services to people with rare neurological problems, My Neuro Survey not only provides a patient view, but gives much needed insights into what services people with ataxia are, and aren't, able to access from the NHS, and their quality in the eyes of patients.”

*Sue Millman, Chief Executive, Ataxia UK
& Alliance Trustee*

Over 10,000 people took part in the 2019 survey. Given the impact of the COVID-19 pandemic on people with neurological conditions and on neurology services, it's even more important that Alliance members support the survey and encourage everyone with a neurological condition (or awaiting diagnosis) to take part.

The survey asks participants questions about whether they are getting the treatment and support they need, including questions about:

- Diagnosis
- Treatment and therapy
- Access to specialists
- Social care
- Employment and financial support
- Support for mental wellbeing
- The impacts of COVID-19 on treatment and care

Data from previous surveys has been used to influence government and health service policy, improve services in individual hospitals, develop new specialist centres and spark debate in Parliament.

How has previous survey data been used?



In major campaigns

Alliance members including FND Hope UK use the condition specific data to underpin their campaigning.

To make the case for new resources

Sue Ryder Care used the data to support the business case for creating new centres.



To improve services



The data has been presented to a wide range of regional groups to inform service improvement, including:

- over 200 GPs in commissioning groups
- Brighton and Sussex University Hospital Trust
- The National Hospital for Neurology and Neurosurgery
- Frimley Care and St George's Hospital, London

To highlight the needs of all people with neurological conditions

Baroness Gale recently used the data in the House of Lords to show how neurological care and support varies across the country.



To put people with neurological conditions at the centre of professional practice

The data is presented to specialist doctors and other health care professionals including The Association of British Neurologists and the British Neuropsychiatry Association, providing unique insight.

creating real change

Who can take part?

Anyone with a neurological condition (or awaiting diagnosis) in England, Scotland, Wales or Northern Ireland can take part. A nominated representative, such as a parent, guardian or carer can fill out the survey on behalf of someone with a neurological condition.

UK wide

The 2021 survey is UK wide and run in partnership with the Neurological Alliances of Scotland and Wales and the Northern Ireland Neurological Charities Alliance (niNCA) for the first time.

For adults, children and young people



There will be two versions of the survey – one for adults with neurological conditions (or awaiting diagnosis) and one for children and young people under 18 with neurological conditions (or awaiting diagnosis).

The parents or guardians of children or young people can fill out the young persons' survey with them.

How can people take part?

Participants will be able to fill out the survey online.

Email miranda.loyd@neural.org.uk to register your interest and receive a unique link to share with your followers and a campaign pack to help you promote the survey online, in print and through social media.

Alternatively, participants can fill out the survey over the phone by calling our survey partners, Quality Health, on Freephone 0800 783 1775.

They can also use this number to:

- Ask for a paper copy of the survey to be sent to their address in the post
- Ask for a large print copy of the survey
- Hear and complete the survey in over 150 languages

Paper copies of the survey will also be available in some neurology clinics.

When will people be able to take part?

The survey will open online on 25th October 2021 and close on 14th January 2022.

How will the survey data be used?

We will use the data to lobby government and healthcare providers, including NHS bodies, to commission, fund and improve care and services for people with neurological conditions. The anonymized results will be collected into a report which will form the basis of our campaigning for the next two years. All participating organisations will get a copy.

Will the survey be anonymous?

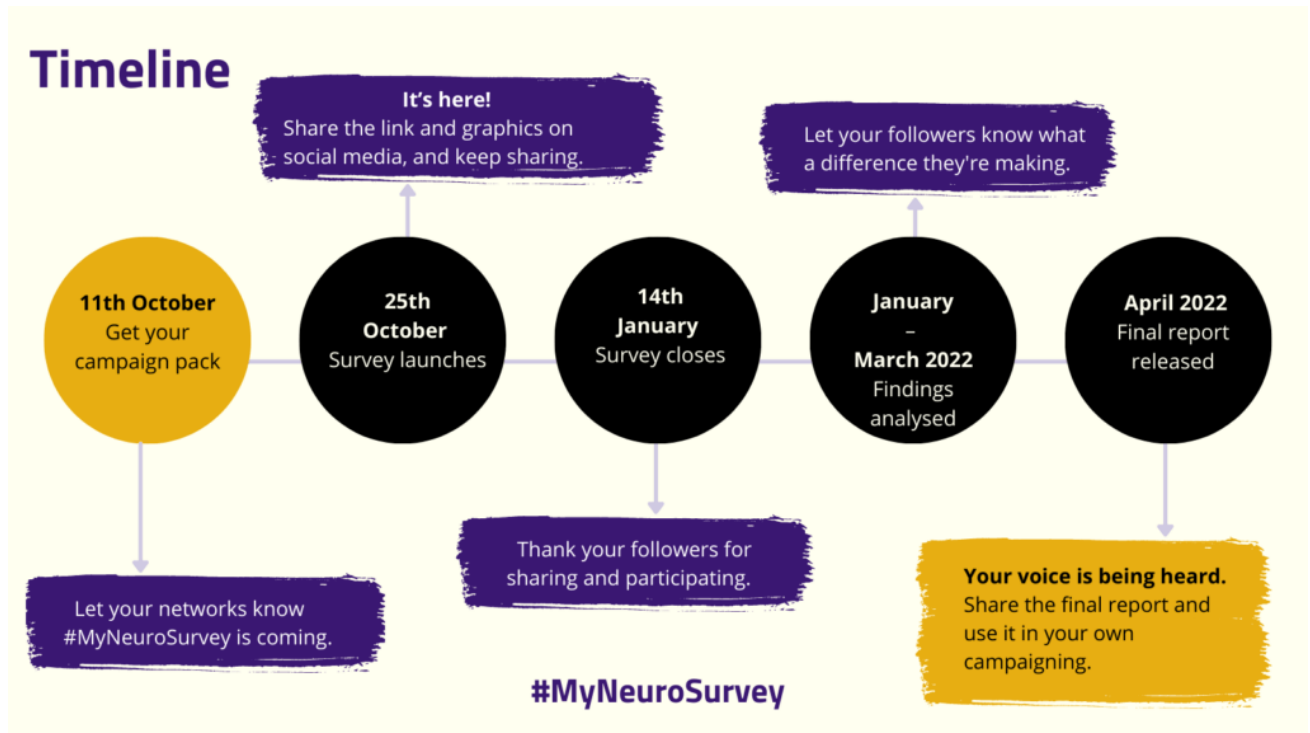
Yes. The survey is completely anonymous. It will not be possible to identify individual participants from their responses. The survey is being carried out by health consultancy Quality Health, a specialist health and social care consultancy with extensive experience of running patient surveys in the NHS.

www.neural.org.uk/supporting-my-neurosurgery

Some people worry that if they say something is wrong, their opinions will be revealed to their health team and it could affect their care. This is not correct. **The survey is carried out by a third party (Quality Health) and they must keep the information confidential by law.**

Ready to support #MyNeuroSurvey?

Get in touch. Email miranda.lloyd@neural.org.uk to request a campaign pack. You will receive the campaign pack on 11th October 2021.



More information

What's in #MyNeuroSurvey for your organisation?

As a member of the Alliance, when you take part, you'll get access to the anonymised data shared by people living with the condition you are most interested in.

If you are more focussed on one region, we hope to be able to provide regional level data too. See an example of a previous survey report [here](#).

Not an Alliance member? Email caroline.davies@neural.org.uk to find out more about membership and how your organisation can benefit.

Making the case for high quality joined up care

My Neuro Survey is designed to collect information from people with neurological conditions about their experiences of treatment, care and support to:

- Help achieve our collective goal of securing joined up care and addressing unwarranted variation in neurological treatment, care and support.
- Create an accurate and detailed picture of the needs and views of everybody with all kinds of neurological conditions, of all backgrounds, ages and walks of life.
- Make the evidence-based case for providing high quality, joined up care and prompt diagnosis to people with neurological conditions.
- Make your views and priorities heard: the results of the survey guide the Alliance's priorities in influencing and campaigning activity.
- Be a resource you can use to support your own campaigning, services and strategies.

Achieving health equality

We're particularly keen to hear from people with neurological conditions who are typically not invited to take part in research and/or people who have limited or no access to services.

This could include black, Asian and minority ethnic groups, the LGBTQI+ community, people with learning difficulties and people for whom English is a second language, refugees or asylum seekers.

About My Neuro Survey and The Neurological Alliance

Who we are

We are a coalition of over 70 organisations working together to transform healthcare outcomes and improve quality of life for people with neurological conditions.

My Neuro Survey is being run in collaboration with the Northern Ireland Neurological Charities Alliance (niNCA), The Neurological Alliance of Scotland and the Wales Neurological Alliance.

Our vision

A world where all people affected by neurological conditions can access high quality care and support to meet their individual needs, at every stage of their life.

Our mission

To raise awareness and understanding of neurological conditions to ensure that every person diagnosed with a neurological condition has access to high quality, joined up services and information from their first symptoms, throughout their life.

The right care at the right time matters.

- We campaign to ensure people affected by neurological conditions can access high quality, joined up care and support to meet their individual needs, at every stage of their life.
- We amplify the voice of the neurological community. In partnership with people with neurological conditions and our member organisations, we gather evidence to make the case for improving the services and care available to people with neurological conditions.
- We work with policymakers and health leaders to push for change and secure high quality services and joined up care for people with neurological conditions.

The right care at the right time can transform quality of life.

Contact

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@NeuroAlliance

#MyNeuroSurvey