

Frequently Asked Questions

What is the My Neuro Survey?

The Neurological Alliance of Ireland is part of a collaborative project with Neurological Alliances in Northern Ireland, Scotland, Wales and England.

The My Neuro Survey collaboration aims to:

- Understand the experiences of people affected by neurological conditions in the UK and Republic of Ireland
- Provide insights to inform future advocacy, influencing, and service improvement at national and local levels

There are **three** surveys:

- An adults' survey – for adults (18yrs and above) with a neurological condition
- A young people and children's survey – for people under 18yrs with a neurological condition
- A carers' survey – for people (18yrs and above) who support someone with a neurological condition or who are completing the survey on behalf of somebody with a neurological condition. This survey explores their experiences and the experiences of the person/people they care for. Parents, guardians and family members, and anyone who provides informal care or support to a person with a neurological condition can complete this survey

Who can take part?

- Adults, children and young people (under the age of 18yrs) with a confirmed or suspected neurological condition
- People who provide support or care for someone with a neurological condition, including parents, guardians and carers
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What are the survey opening and closing dates?

The survey will run from **22nd July 2024 – 15th November 2024**

Is the survey anonymous?

Yes, the survey is completely anonymous. It is not possible to identify individual participants from their responses.

Who is running the survey?

The survey is run by the Neurological Alliance of Ireland in partnership with the Neurological Alliances in England, Scotland and Wales and the Northern Ireland Neurological Charities Alliance

What topics does the survey cover?

- You and wider life
- The wider impact of
 - your neurological condition(s)
 - or the neurological condition(s) of the person you care for
- Your experience and overall feelings of healthcare and your reflections

How will my data be processed?

This survey is conducted by Revealing Reality (a research company) on behalf of the Neurological Alliances. By answering the survey, participants will share their responses with the Revealing Reality research team. **All information will be stored securely, remain anonymous, and will only be used for this research project.** All shared information will be destroyed when it is no longer needed for the project, and all data will be processed in compliance with GDPR regulations.

How will the results be used?

Here in Ireland, we will use the information from the survey to lobby government and healthcare providers to improve care and services for people with neurological conditions

Who do I contact if I have any queries

The survey is live from 22nd July to 15th November 2024. If you have any queries about completing the survey, or to request a paper survey, e mail the Neurological Alliance of Ireland advocacy@nai.ie