Supplier brief

My Neuro Survey 2024: developing and delivering an influential and inclusive UK-wide neurological patient experience survey

Who we're looking for

We are looking for a market research or survey provider to work with us to develop and deliver the next iteration of the national neurological patient experience survey starting in January 2024 to April 2025.

The survey is our flagship biennial research project aiming to capture the experiences of people who live with a neurological condition such as epilepsy, multiple sclerosis (MS), dystonia, functional neurological disorder (FND), motor neurone disease (MND), headache or stroke and over 600 other known conditions. At least 1 in 6 people live with a neurological condition across the UK.

As the largest survey of its kind for people affected by neurological conditions, My Neuro Survey is a vital and respected source of patient experience data and insight. Evidencing the challenges and needs of our community is critical to making the case for much needed service improvement and political prioritisation.

The survey is well respected and referenced across NHS services, healthcare professionals, policymakers, UK governments the third sector and beyond. We need to work with an experienced market research agency to build on this success, and help to deliver the biggest, most inclusive and impactful survey yet.

Proposed objectives of the survey

- Capture the experiences of people affected by neurological conditions and provide both raw and thematically organised or tabulated quantitative data and content analysis of qualitative data
- Provide a robust patient experience data set – with a target of at least 12,000 responses across the UK with a proportionate split of nation level responses
- Support advocacy, influencing, campaigning and service improvement.
- Support membership campaigning, influencing and policy development, through condition specific analysis of the results.
- Support clinic improvement, through clinic specific analysis of the results for participating clinics.
- Ensure the survey is accessible and inclusive for everyone with or with a suspected neurological condition
- Build broad support for the survey from key stakeholders including Neurological Alliance member organisations across the UK, people affected by neurological conditions, clinical colleagues, system leaders and others

Previous iterations of the survey have been rolled out online and in clinics. The survey methodology along with the survey questionnaire require reviewing and revising as necessary to deliver an influential and inclusive survey.

As an infrastructure and member organisation, and given the wide variety of stakeholders who will have to be meaningfully engaged with the survey process, including people affected by neurological conditions, relationship building and stakeholder management will be critical to the success of the project.

Oversight of the project will be provided through a Steering Group comprised of key stakeholder including Alliance member organisations, Neurological Alliances from across the UK and people affected by neurological conditions.

Key stakeholders

- People affected by neurological conditions, including stroke and dementia, both adults and children and young people, as well as parents and carers
- Voluntary, Community and Social Enterprise (VCSE) organisations, including Alliance members
- Professional bodies
- Clinical colleagues, including clinical leads and service managers
- Local health boards and systems, including Integrated Care System leads
- National decisionmakers in health and care across the UK.

Scope and outputs

The survey will be conducted across the UK. Survey design and delivery to include project management of the areas below, including travel and attending meetings where required:

Methodology development

- Methodology development informed by separate listening and engagement exercises (outside of the scope of this brief), previous survey evaluations and input from key stakeholders.
- Agreement of proposed methodology with the Alliance and Survey Steering Group, with revisions being incorporated where appropriate.

Questionnaire pilot and development

- Questionnaire development (up to x3 questionnaires – children and young people (under the age of 18), adults, and carers) and piloting in at least 3 - 5 clinical sites.
- Revise the questionnaires based on feedback from the pilot.
- Manage discussion and production of questionnaire drafts.
- Conduct cognitive tests of up to three revised questionnaires with young people, adults and carers, affected by neurological conditions.
- Provide questionnaires in different formats (e.g. easy read) and languages, to support inclusivity and diversity.
- Design and production of paper copies of the questionnaires, as needed

Survey distribution and reporting

- Re-design and develop the online platform with capacity to track and monitor responses by point of referral (for example using unique links).
- Run large-scale online surveys to be distributed widely and via Neurological Alliance and other UK Neurological Alliance member organisations.
- Print and distribute paper questionnaires to as many neurological units as needed across the UK, with a target of securing the participation of at least 80% of neuroscience centres.
- Produce fortnightly reports on response rates, including by condition, nation, and protected characteristics, so that targeted outreach and prompts can be carried out.
- Liaise with services, including neurology outpatient clinics, to support survey completion and logistics management.

Data collection and analysis

- Collect and process data of all returns, in line with data protection regulations and agreed privacy impact assessment
- Report and analyse all data, including thematic content analysis of all qualitative data
- Provide clean data tables
- Interim presentation after the first 500 questionnaires are completed
- Deliver two presentations post completion of all three surveys, which might be in person

We welcome suggestions on the scope of the brief from prospective suppliers.

The full technical report from the previous survey is available here: https://www.neural.org.uk/togetherforthe1in6/

Timings and milestones

To be finalised in consultation with successful provider and our partner organisations.

- Project scope and initiation: January 2024
- Design of survey and methodology: February – April 2024
- Pilot of survey and methodology: April 2024
- Revise survey and methodology (if necessary): May 2024
- Rollout of full questionnaire: July – October 2024
- Data analysis: November 2024 – January 2025
- Reporting: January – February 2025
- Launch of data: April 2025

About you

We welcome applications from people and organisations from all backgrounds and walks of life, particularly people from often underrepresented groups. These include people with disabilities and/or people from Black, Asian and minority ethnic backgrounds and the LGBTQIA+ community. We are committed to promoting equity, diversity and inclusion through our work and within and beyond our organisation.

For this role, we are looking for organisations and teams with the following skills and experience:

- Shares The Neurological Alliance's values and our mission
- Are highly organised and able to engage with clinics across the UK
- A proven track record in healthcare research, survey design, and data analysis specific to patient experience measurement
- Utilises digital and innovative analysis techniques to make the most out of the data and support efficient working
- High quality reporting and analytical expertise
- Excellence in data security and compliance
- Highly collaborative: you will be working alongside our members, people affected by neurological conditions and policymakers. You need to be able to work as part of a team and collaboratively with them.
- Experience of working closely with lived experience partners, ideally with people affected by neurological conditions
- Is accessibility and inclusion aware
- Understands the technical requirements of the brief.

How to apply

Send a short pitch to info@neural.org.uk outlining how you would approach the project to achieve its aims and meet the deadline.

This could be a short video (up to five minutes) or a written statement (no more than 1000 words). You can include pictures and links to support your pitch.

Your pitch should cover:

- Please provide a brief overview of the people/team who will be directly working on the project, and the skills and experiences which make them well-suited to the brief? What attracted you to it?
- Please share with us what diversity, equity, and inclusion mean to you and why they're important. How would you put the principles of diversity, equity and inclusion into practice in this project, including working inclusively with people living with neurological conditions and disproportionately impacted by health inequalities?
- How would you make sure the survey was as effective as possible?
- Talk us through your proposed approach to meet the technical requirements of the project: a brief outline project plan, methodology, indicative budget breakdown, key risks and how they will be managed.
- We'll be working to some tight deadlines: how will you make sure these are met?

We are inviting pitches from a range of providers. Your pitch will be assessed on the following criteria:

- Value for money.
- Demonstrable experience of delivering high-quality surveys, particularly in relation to similar areas of work e.g. patient experience surveys.
- Experience of writing and presenting complex information and data to a diverse range of audiences, including patients, policy makers, and the wider public.
- Reputable, responsive and reliable provider, with sufficient capacity to carry out the project.
- Scope of services being offered.
- Ability to effectively and inclusively run a UK-wide survey, which also engages communities which are underrepresented in research.
- Extent to which the proposed approach will meet the requirements, including the feasibility of the project plan and cost breakdown, and appropriateness of the methodology.
- Relevant diversity, equity and inclusion knowledge and practice, with effective approach towards embedding it in the project.
- Comprehensive understanding for risk and appropriate risk mitigation strategies.

Fee

Please submit an estimate of the cost of the project with your pitch, with an upper limit of £60,000 including VAT. The cost estimate should cover all activities expected to be incurred to complete the project.

Contract timeline

- Issue of supplier brief – Tuesday 23rd January 2024
- Tender submission deadline –Tuesday 13th February 2024 at 11:59pm
- Interview prospective suppliers – W/c Monday 19th February 2024
- Appointment confirmation and contracting – Wednesday 28th February 2024
- Supplier start date - as soon as possible, subject to mutual agreement

Contact

- For more information or if you have any questions please contact us: info@neural.org.uk or 01923 882 590
- If you need this information in an alternative format, please contact us.

Appendix 1 – Context

The Neurological Alliance is England's leading coalition of patient groups, professional bodies and organisations supporting the one in six of us with a neurological condition. Alongside our 90+ members and people with lived experience, we work to ensure that every person affected by a neurological condition can access the right treatment, care and support at the right time.

Between October 2021 and March 2022, we ran the fourth iteration of the national neurological patient experience survey, My Neuro Survey. The survey is the largest of its kind, receiving over 8,500 responses and open to everyone with or with a suspected neurological condition across the UK. The survey is delivered in partnership with the Neurological Alliance of Scotland, the Northern Ireland Neurological Charities Alliance and the Wales Neurological Alliance.

Along with the support of our diverse membership, My Neuro Survey was endorsed by leading professional bodies including the Association of British Neurologists (ABN), British Paediatric Neurology Association (BPNA) and the Royal College of Psychiatry, Neuropsychiatry Faculty and Neurological Alliances across the UK.

The data and insights informed a series of policy reports, Together for the 1 in 6, shining a spotlight on the key challenges facing our community including a lack of mental wellbeing support, delays to life changing treatment and care and inadequate information and support at diagnosis. The reports were launched in Parliament with dozens of MPs and Peers attending and a subsequent House of Lords Grand Committee Debate both of which garnered cross-party support for the report and recommendations.

Our accompanying Back the 1 in 6 campaign calling on governments across the UK to establish a Neuro Taskforce and deliver real change on these challenges is supported by more than 100 organisations and over 19,000 petition signatories.

We will build on these successes and our extensive experience developing and delivering My Neuro Survey, to deliver an influential and inclusive next iteration of the survey to evidence experiences and drive much needed improvements to services and support for people affected by neurological conditions.