

My Neuro Survey – Data Briefing

Experiences of respondents to the children and young people's My Neuro Survey

Executive Summary

An estimated one in six of us lives with a neurological condition¹. Neurological conditions can affect anyone at any age, including children and young people.

For the first time our national neurological patient experience survey, My Neuro Survey, included a version specifically for children and young people in the UK with or with a suspected neurological condition.

My Neuro Survey included questions about the impact of COVID-19 on treatment and care, mental health and wellbeing, diagnosis, and access to specialists. Many questions were the same as those included in the adult survey. However, there were additional questions specifically for children and young people, aiming to capture their experiences of education and the transition from child to adult services.

The experiences of over 8,500 respondents across both surveys informed a series of policy reports titled "Together for the 1 in 6". These spotlighted common challenges facing people with neurological conditions across the UK. The reports and initial data sets are available [here](#).

Together with Neurological Alliances in Wales and Scotland and the Northern Ireland Neurological Charities Alliance (niNCA), over 100 organisations and 13,500 people to-date, we're calling on all UK Governments to work together to establish a Neuro Taskforce to

¹ The Neurological Alliance (2019), Neuro Numbers - <https://www.neural.org.uk/assets/pdfs/neuro-numbers-2019.pdf> (accessed, 15/09/22)

address common challenges and deliver real change. Show your support by signing the [petition](#).

This briefing will focus on responses and experiences of children and young people under 18 years old shared through the children and young people's version of My Neuro Survey. As well as spotlighting the experiences of children and young people living with a neurological condition or suspected neurological condition in 2021/22, the data will also provide a baseline to track and compare experiences shared in future surveys.

Summary of findings

- **Delays to treatment and care** – more than 4 in 10 (n=162) respondents to the children and young people's survey reported a delay to a first appointment with a specialist for their neurological condition in the last 12 months. 6 in 10 (n= 305) reported a similar delay to a routine appointment with a specialist.
- **Mental health and wellbeing** – respondents to the children and young people's survey reported significant impacts of their neurological condition and the pandemic on their mental health and wellbeing:
 - Respondents to the children and young people's survey were significantly more likely than adults to report that their mental health or behaviour had worsened during the pandemic.
 - Almost 9 in 10 (n=506) respondents to the children and young people's survey reported that their neurological condition makes their mental wellbeing worse.
- **Information at diagnosis** – 20% (n=89) of respondents to the children and young people's survey reported not receiving any information when they first found out about their condition.

- **Transition from child to adult services** – 85% (n=250) of children and young people to whom the question was applicable reported not having a named worker to support their transition to adult services but would find this helpful.
- **Education** – neurological conditions have a significant impact on school attendance, with more than 7 in 10 respondents (n=406) reporting that their attendance has been affected by their condition.

About respondents to the children and young people’s survey

629 people completed the children and young people’s survey:

- 87% (n=545) of respondents reported being the parent of a child or young person living with a neurological condition.
- 11% (n=69) of respondents reported being a child or young person under the age of 18.
- 2% (n=12) of respondents reported as other.

Reported neurological conditions

The table below shows top three reported neurological conditions for respondents to the children and young people’s survey and for the adult survey.

Epilepsy is the [most common long term neurological condition](#) among children and young people in the UK² and was the most reported condition among respondents to the children and young people’s My Neuro Survey.

	All respondents to the children and young people’s survey	All adult respondents
1st most reported	Epilepsy 28% (n=179)	Multiple Sclerosis (MS) 16% (n=1,245)
2nd most reported	Tourette syndrome 19% (n=118) Hydrocephalus 19% (n=119)	Epilepsy 13% (n=1,006)
3rd most reported	Autism 16% (n=102)	Migraine 11% (n=851) Functional Neurological Disorder (FND) 11% (n=849)

Table 1: Conditions reported

² Royal College of Pediatrics and Child Health (2020), State of Child Health <https://stateofchildhealth.rcpch.ac.uk/evidence/long-term-conditions/epilepsy/> (accessed on 15/09/2022)

Nation

The graph below shows the nation of respondents to the children and young people's survey, identified by reported postcode:

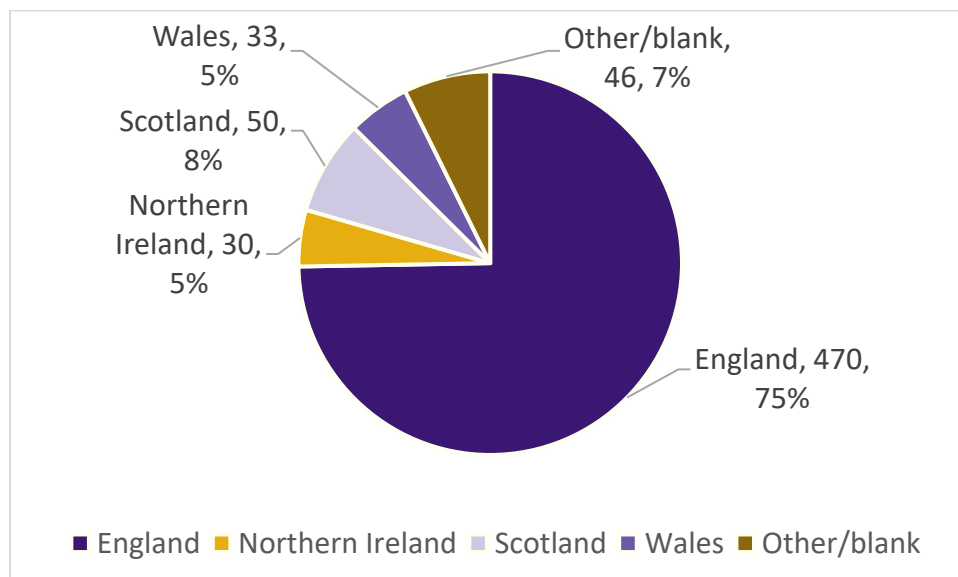


Figure 1: Nation of Children and Young People My Neuro Survey respondents

Age

The graph below shows the age of respondents to the children and young people's survey:

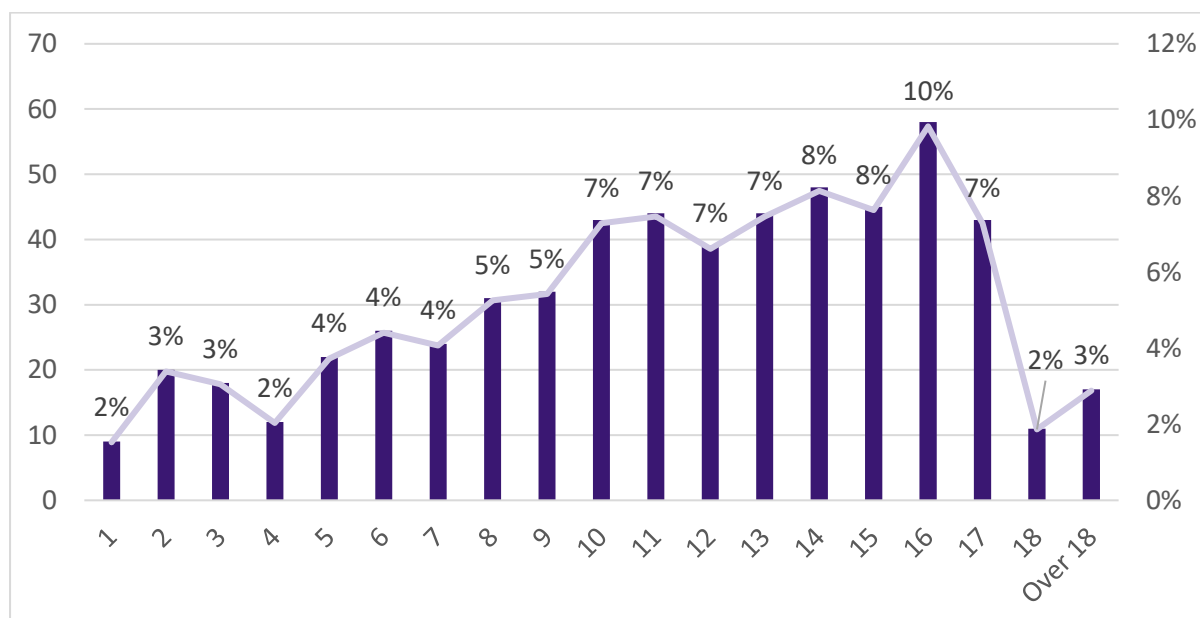


Figure 2: Age of Children and Young People My Neuro Survey respondents

Gender

The graph below shows the gender of respondents to the children and young people's survey:

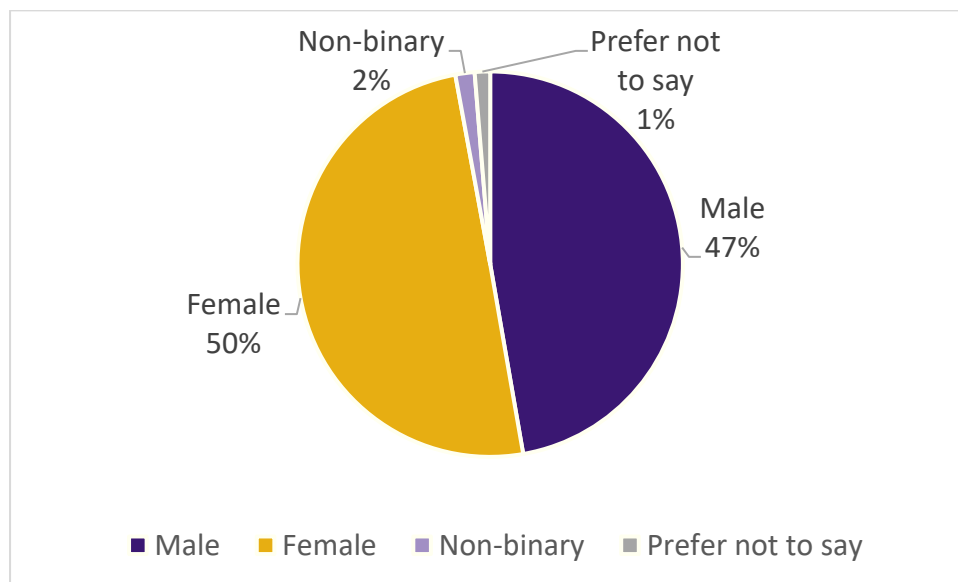


Figure 3: Gender of Children and Young People My Neuro Survey respondents

Analysis

The analysis highlights experiences of respondents to the children and young people's survey. A key focus of the analysis is areas of common challenges facing people with neurological conditions of all ages as set out in our "Together for the 1 in 6" UK policy report and #BackThe1in6 campaign:

- Delays to treatment and care
- Mental wellbeing support
- Information at diagnosis

Attention has also been given to topics and questions that were only included in the children and young people's survey including education and transition from child to adult services.

Delays to treatment and care

“After a year and a half on waiting list we have now been move to priority. Unfortunately that is a priority waiting list.”

More than 4 in 10 respondents to the children and young people’s survey to whom it was applicable reported a delay to a first appointment with a specialist for their neurological condition in the last 12 months. 6 in 10 reported a similar delay to a routine appointment with a specialist.

- 44% (n=162) of respondents reported a delay to a first appointment with a specialist for their neurological condition compared to 33% (n=1,071) of adults.
- 60% (n= 305) of respondents reported a delay to a routine appointment with a specialist for their neurological condition compared to 55% (n=2,951) of adults.

60% (n=179) of respondents to the children and young people’s survey to whom it was applicable reported a delay to a mental health appointment in the last 12 months.

46% (n=103) respondents to the children and young people’s survey to whom it was applicable reported a delay to speech and language therapy in the last 12 months – double the percentage of adult respondents of whom 23% (n=357) reported the same.

39% of (n=77) respondents to the children and young people’s survey to whom it was applicable reported a delay to wheelchair services in the last 12 months.

More than half of respondents to the children and young people’s survey (52%, n=275) reported waiting less than 3 months between first seeing a GP and seeing a hospital-based specialist (paediatrician or paediatric neurologist).

Mental health and wellbeing

“We had a few sessions online with CAMHS [Child and Adolescent Mental Health Services], which again we waited almost 4 years for. They were not particularly useful. When my daughter's mental health went downhill shortly afterwards, they refused to see her and said we had to start the process of applying again! We've been paying for private therapists.”

More than 6 in 10 respondents to the children and young people's survey (63% n=349) reported that their mental health had worsened during the pandemic.

Almost 9 in 10 respondents to the children and young people's survey reported that their neurological conditions made their mental wellbeing worse.

Over half (56%, n=317) reported that their neurological condition makes their mental wellbeing much worse.

A further third (33%, n=189) reported that it made their mental wellbeing slightly worse.

62% (n=205) of respondents to the children and young people's survey to whom it was applicable reported not being offered counselling but would find this helpful.

36% of all respondents reported not being offered or directed to support for their mental wellbeing by a health care professional in the last three years but would have liked this.

66% of respondents to the children and young people's survey reported their mental wellbeing needs were being met to a small extent (31%, n=159) or most often, not at all (35%, n=179).

Information and support from diagnosis

“We have had to fight for support for our child and left hospital following brain surgery with little or no information and certainly no ongoing support.”

This set of questions were only answered by respondents who reported receiving a diagnosis of their neurological condition within the last 10 years (79%, n=494).

Almost a quarter of respondents to the children and young people’s survey (23%, n=105) reported that their diagnosis was handled poorly, including the way in which they were told about their condition and how sensitive the healthcare professional was when telling them.

20% of respondents to the children and young people’s survey (n=89) reported not being given an explanation at diagnosis or when they first found out about their neurological condition.

A third of respondents to the children and young people’s survey (33%, n=165) reported not being offered or directed to any information when they were told they had a neurological condition

When asked about the usefulness of the information received, almost half of those who received information about their condition at diagnosis (48%, n=176) reported that it was fair (25%, n=91) or poor (23%, n=85).

Transition

“We've decided to seek support privately as my daughter's condition is deteriorating and we don't feel the adult team will provide the support she needs.”

Having a named worker to support the transition from child to adult services is recognised and evidenced as best practice by the National Institute for Health and Care Excellence (NICE).

- [NICE guideline \[NG43\]](#) “Transition from children’s to adults’ services for young people using health or social care services”³
- [NICE quality standard \[QS140\]](#) “Transition from children’s to adults’ services”⁴

Despite this, over 8 in 10 respondents to whom the question was applicable reported not having a named worker to support their transition but would find this helpful.

85% (n=250) reported that they had not been offered a named worker to support the transition process between paediatric and adult services but would find this helpful.

³National Institute of Health and Care Excellence (2016), Transition from children’s to adults’ services for young people using health or social care services [NG43]
<https://www.nice.org.uk/guidance/ng43/chapter/Recommendations#support-before-transfer> (accessed 16/09/2022)

⁴ National Institute of Health and Care Excellence (2016), Transition from children’s to adults’ services [QS140]
<https://www.nice.org.uk/guidance/qs140/chapter/quality-statement-3-named-worker> (accessed 16/09/2022)

Education

The graph below shows the reported current schooling or education situation of respondents to the children and young people's survey:

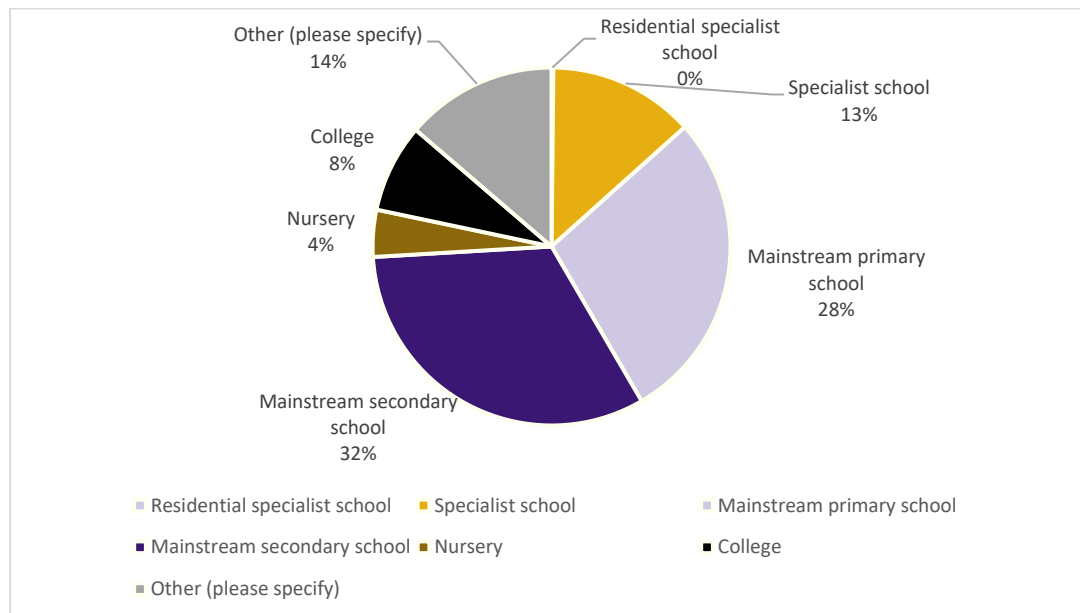


Figure 4: Schooling or education situation of Children and Young People My Neuro Survey respondents

More than 7 in 10 respondents (71%, n=406) agreed that their attendance at school has been affected by their neurological condition.

43% (n=255) reported being offered an education, health and care (EHC) plan. An EHC plan is for children and young people in England aged up to 25 who need more support than is available through special educational needs support.

63% (n=339) of respondents agreed that their school has made useful changes to help them to attend.

16% (n=89) of respondents disagreed that staff involved with their education listened to them.

Access to emergency care

Respondents to the children and young people's survey were significantly more likely to report an emergency hospital admission due to their neurological condition in the past two years compared to adult respondents.

51% (n=316) of respondents reported no emergency admissions in the past two years compared to 74% (n=5,719) of adult respondents.

29% (n=183) of respondents reported 1–2 emergency admissions in the past two years compared to 18% (n=1,414) of adult respondents.

12% (n=77) of respondents reported 3–5 emergency admissions in the past two years compared to 4% (n=329) of adult respondents.

Access to treatment and support, including remote consultations

“Because my neurological condition is invisible I am often ignored and treated as if I don't have a legitimate problem”

When asked how they felt about more appointments being delivered remotely, more than 7 in 10 respondents (73%, n=455) reported that they like talking to their doctor or healthcare professional in person the most.

10% of respondents (n=56) reported not feeling confident using the technology needed for a remote consultation.

25% of respondents (n=139) reported that they did not find remote consultations useful.

20% of respondents (n=112) reported that their healthcare professional did not call when they expected them to.

15% (n=48) of respondents to the children and young people's survey to whom it was applicable agreed that the social care they receive meets their needs.

A third of respondents (n=193) reported that they found it either very difficult (11%, n=62) or difficult (22%, n=131) to travel to the majority of appointments for their neurological condition.

Financial wellbeing

54% (n=327) of respondents to the children and young people's survey reported being in receipt of Personal Independence Payments (PIP) or Disability Living Allowance (DLA) compared to 43% (n=3,308) of adult respondents.

30% (n=181) of respondents to the children and young people's survey reported being in receipt of Carer's Allowance.