



THE
NEUROLOGICAL
ALLIANCE

Epilepsy Resource Navigator Tool

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Overview

- About us and what we do
- The Epilepsy Service Navigator tool
- What next

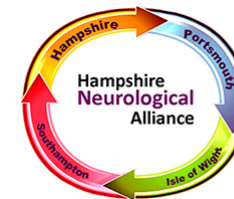
About the Neurological Alliance

- **Vision:** Every person affected by a neurological condition can access the right treatment, care and support at the right time.
- **Mission:** To harness the energy and passion of the neurological community to ensure public policy in health reflects the realities of living with a neurological condition, so that everyone can access treatment, care and support whenever they need it.

PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.



British Society of
Rehabilitation Medicine
Promoting quality through
education and standards

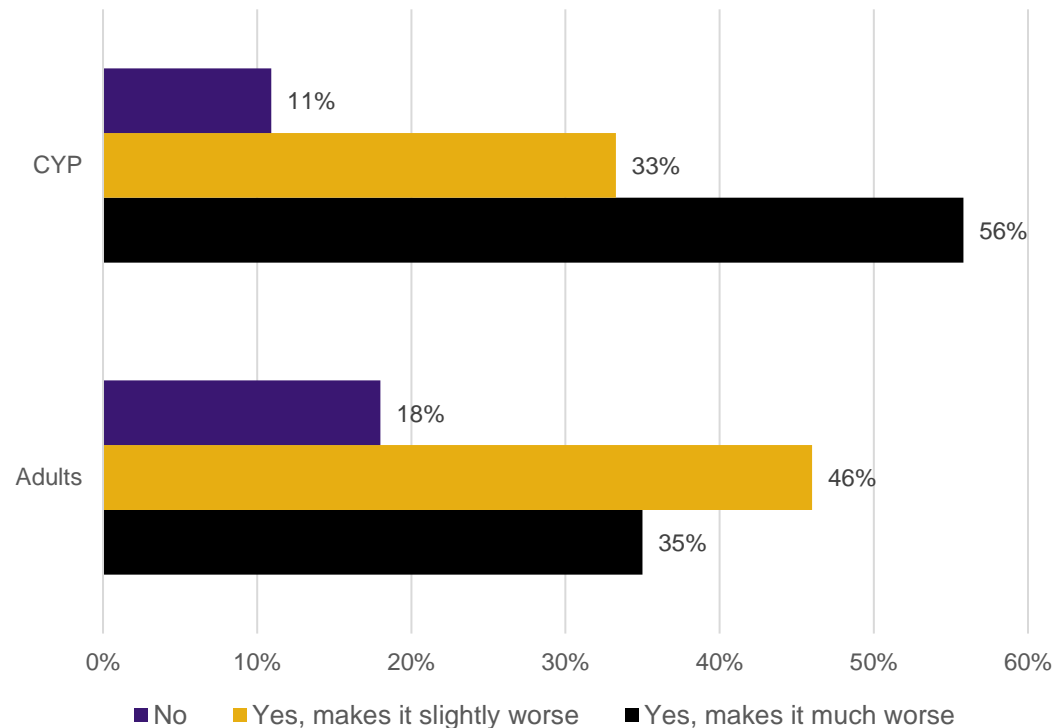


Developing evidence for change

- Develop a range of tools and resources to support transformation and change in services.
- About My Neuro Survey 21/22:
 - Fourth Patient Experience survey conducted by the Alliance.
 - Delivered in collaboration with the Wales Neurological Alliance, Neurological Alliance of Scotland and the Northern Ireland Neurological Charities Alliance (niNCA).
 - Responses collected between 25 October 2021 – 6 February 2022.
 - Rolled out across 35 clinics, through our membership and other partners.
 - Endorsed by the ABN, BPNA, Royal College of Psychiatry and ACPIN.
 - More than 8.5k responses received.
- Optimal clinical pathways for a range of conditions.

Neurological conditions have a significant impact on mental wellbeing which has been made worse by the pandemic

Does your neurological condition affect your mental wellbeing?



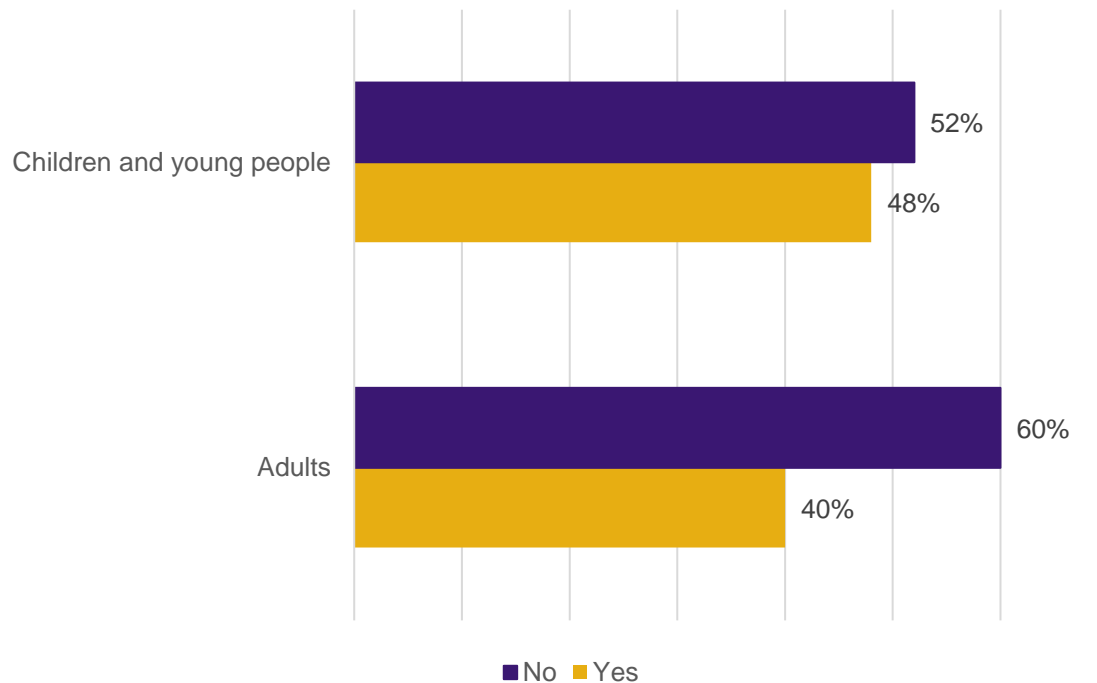
- (Adults) Have you experienced a change in your mental health needs due to COVID-19?
- (CYP) Have you experienced a change in your mental health or behavior during the pandemic?

	Adults (%)	CYP (%)
Yes, my mental health has worsened	44%	63%
Yes, my mental health has improved	3%	4%
No, my mental health has remained the same	53%	33%
I am unsure	12%	11%

Too many people are not being asked about, signposted or referred to support for their mental wellbeing

Have you been asked about your mental wellbeing by a health or social care professional in the last three years?

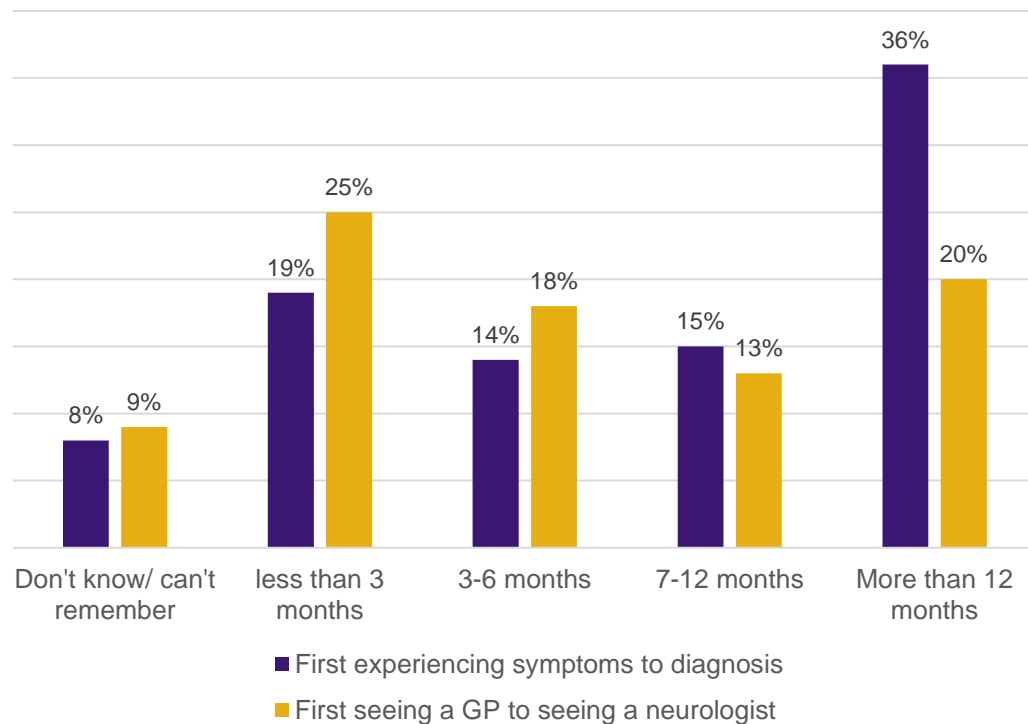
Have you been referred or directed to support for your mental wellbeing by a health professional within the last three years?



	Adults (%)	CYP (%)	2018/19 (%)
Yes	23%	39%	26%
No, but I would have liked this	36%	36%	30%
No, and I did not want/ need this	41%	25%	44%

Too many people continue to face long waits to see specialists and get a diagnosis

How long were you waiting between...



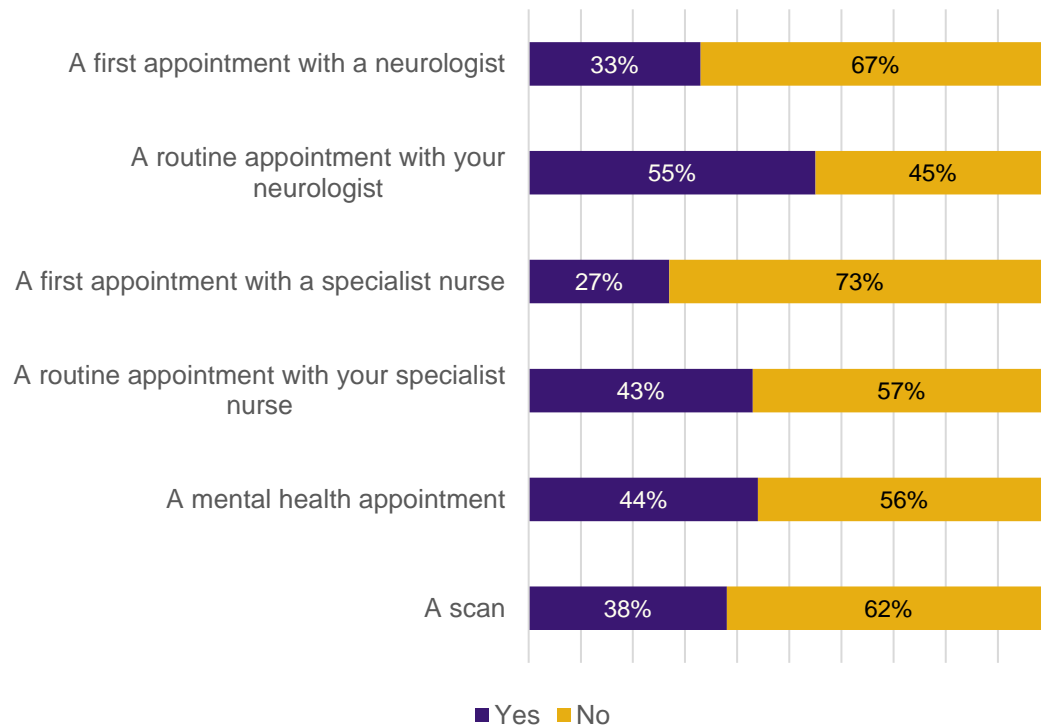
- Women, those living in more deprived areas and those living in England (compared to other UK nations) were more likely to report longer waits.

“After 2 years of being passed from pillar to post I was eventually seen by a Physiotherapist who recognised my symptoms and referred me to see a Neurologist who after just 10 minutes diagnosed me with Parkinson's disease. If I had been diagnosed 6 months earlier I might have been able to keep working but without the correct medication I just couldn't function. “

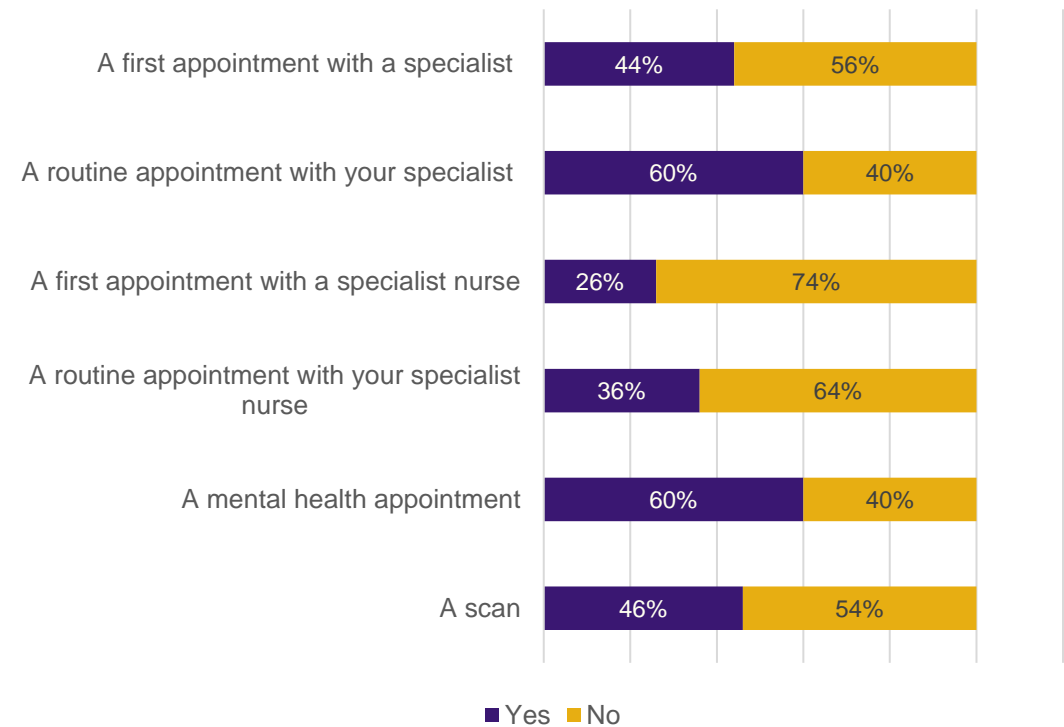
People with neurological conditions faced significant delays to treatment and care in the last year

Have you experienced delays to your neurological care or treatment in the last 12 months?

Adults

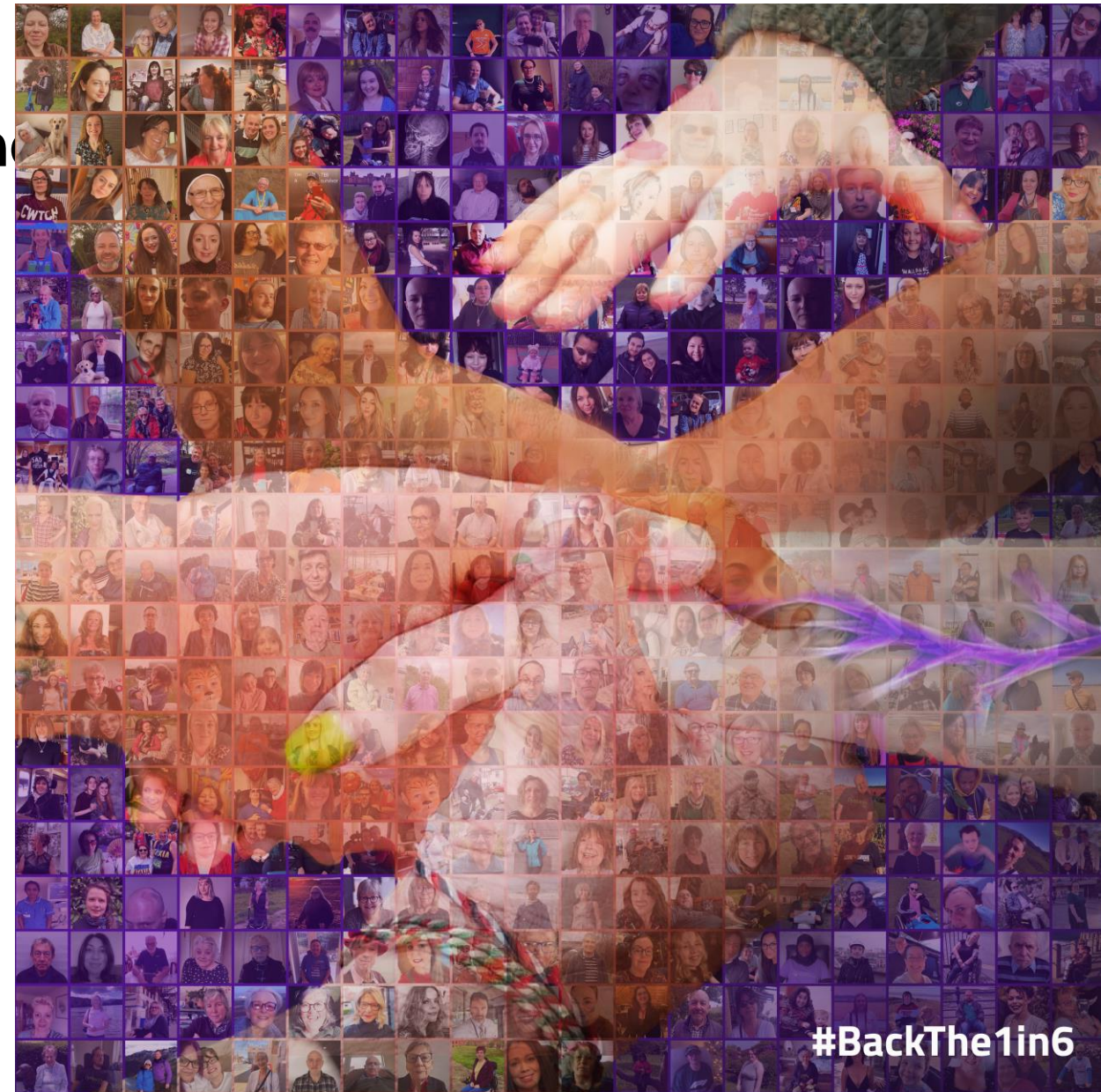


Children and young people



Campaigning for change: #BackThe1in6

- 19,000 people spoke up for the 1 in 6.
- Parliamentary launches in Westminster and Holyrood. More than 20 MPs spoke up in support of the campaign.
- 300 people shared their 'Pics for the 1 in 6' – 5,000 have viewed.
- More than 1000 people engaged their GE candidates – 12 elected MPs pledged support as a 'Neuro Champion'
- Community services have been developed using survey data.
- Important wins on national policies – NHSE transformation programme, new neuro data in the health service, manifesto pledges on neuro.



Influencing public policy

- Hold key roles in NHSE and DHSC
- Current focus:
 - NHS 10-Year Plan
 - Elective care reform
 - Encouraging UK collaboration on neuro
 - Development of key service specs
 - NHSE Neuro transformation programme
 - Building awareness in Parliament



About the Epilepsy Service Navigator tool

Overall project aim: To reduce unwarranted variation in adult and pediatric epilepsy services in England through enhanced service improvement

Overview of Project: The Neurological Alliance will develop a succinct navigation tool, providing an overview of the resources available in epilepsy, including the RightCare toolkit, NASH audit, Epilepsy12, NICE guidelines and Neurological Alliance Patient Experience Survey. The tool will support interested parties to find and utilise the resources available to support epilepsy service improvement

Project Scope: Services commissioned for people with epilepsy in England

Primary target user: ICS stakeholders, Providers (managers), clinical leaders

The project was sponsored by UCB. UCB had no influence over the content of the tool.

Expert advisory group

Clinical specialists (adult services)	Clinical specialists (paediatric services)	Primary Care	Patient Organisations	Strategic leads
Sofia Eriksson, Consultant Neurologist, ABN Epilepsy Advisory Group	Maria Gogou, Paediatric Neurologist, BPNA	Ian Minshall, GP with a special interest in epilepsy	Georgina Carr, Chief Executive, Neurological Alliance	Julie Riley, Deputy Director of Strategy, The Walton Centre
Tony Marson, Consultant Neurologist, NHSEI Neuroscience Programme Optimum Clinical Pathway for epilepsy lead	Robert Robinson, Paediatric Neurologist, BPNA		Angie Pullen, Programme Lead, Epilepsy Research UK	
Carrie Burke, Epilepsy Specialist Nurse, ESNA	Laurie Bibby, Paediatric epilepsy specialist nurse, Alder Hey Hospital		Alison Fuller, Director of Health Influencing and Improvement Epilepsy Action	
Christine Cole, Epilepsy Specialist Nurse, ESNA			Sammy Ashby, Deputy Chief Executive, SUDEP Action	
			Rosemarie Pardington, Director of Integrated Care, Young Epilepsy	

Tool priorities

The expert advisory group agreed the tool must:

- capture the complexity of epilepsy in a simple way
- Be easy to engage with
- Position epilepsy as a system wide priority and support commissioners to tackle system wide pressures.
- Make clear that action to improve services for people affected by epilepsy is in line with national objectives, as outlined in NHSE/I operational guidance.
- Focus on the “how to”, complimenting the NICE guidelines/quality standards
- Align with the priorities of key products & initiatives inc. NHSEI neuroscience transformation programme, NHSEI epilepsy oversight group, NICE Quality Standards, NCEPOD
- Address “full pathway development” so that users can see who is involved from beginning all the way through

Our approach

- Focussed review of available literature evidence
- Agree segmentation model for the tool
- Further test priorities through stakeholder interviews with commissioners, healthcare professionals and people affected by neurological conditions
- Build and test tool
- Promote!

Structure



- Epilepsy and the system
- Commissioning to meet the needs of the epilepsy population
- Commissioning resources to meet the pathway needs of the epilepsy population
- Commissioning resources to meet the pathway needs of specific groups of the epilepsy population
- Developing a business case
- Partnering with the epilepsy community

How to use the tool

- Find it on our website (<https://www.neural.org.uk/wp-content/uploads/2023/06/Epilpsy-Navigator-Tool-v10.pdf>)
- Simply use the search page to navigate to the area of interest. You can also work through each section in order.



What next?

- New tool for MS to be published soon
- My Neuro Survey results 24/25 out in summer 2025 – should include ICS level data
- Our “tests” for the NHS 10-year plan will be published before the end of the year