

Written evidence submitted by The Neurological Alliance (CBP0062)

About us

- The Neurological Alliance is a coalition of more than 70 organisations working together to transform quality of life for people affected by neurological conditions in England.
- A neurological condition is any condition that affects the brain, spine and/or nerves. There are over 600 types of neurological conditions, some which are comparatively common such as migraine, multiple sclerosis (MS) and epilepsy, and others which are rare. They can be sudden, fluctuating, progressive and/or lifelong and have a range of different causes including genetic factors, traumatic injury and infection, although the causes of some neurological conditions are still not well understood.
- Around one in six people in the UK have at least one neurological condition with an estimated 600,000 people diagnosed each year, they can affect anyone at anytime.
- Together 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.

Access to services

- Many people with neurological conditions had difficulty accessing the treatment and care they need long before the pandemic.
- Findings from the 2018/19 National Neurology Patient Experience Survey¹ of more than 10500 people across England, showed that almost 30% of respondents who needed to see a neurologist waited more than 12 months for an appointment while 55% reported delays in accessing health care.
- Significant unwarranted variation in waits for care were also reported. For example, a higher proportion of women reported waiting more than 12 months to see a neurologist (32% of women compared to 20% of men). A higher proportion of women reported to have seen their GP five or more times before being referred (43% of women compared to 27%). Conversely, a higher proportion of men reported having seen their GP once or twice before being referred to a neurologist (36% of women to 53% of men). To our knowledge, there is not clinical justification for this variation in experience.
- The pandemic has compounded existing issues face by people with neurological conditions when attempting to access health services.
- In a Neurological Alliance survey from June 2020 72% of respondents had reported delays to medical appointments during the pandemic², of those 43% had not been given a new date for their appointment.

¹ <https://www.neural.org.uk/publication/neuro-patience/>

² <https://www.neural.org.uk/wp-content/uploads/2020/07/20200703-Final-Restarting-Services-for-People->

- Latest waiting times data from NHS England and NHS Improvement³ shows that the number of people waiting to start neurology and neurosurgery treatment continues to rise month on month.
- The number of people waiting to start neurology treatment in June 2021 stands at 140,482 up from 134,245 in May 2021. Year on year this is an increase of almost 40,000 people. Of those waiting to start treatment, 2% have been waiting for over a year – we estimate this to be a rise from approximately 100 people to more than 2500.
- The number of people waiting to start neurosurgery treatment in June 2021 stands at 45,845 up from 44,965 in May 2021. Year on year this is an increase of almost 12,000 people. Of those waiting to start treatment, 7% have been waiting for over a year up 5% year on year.
- The latest data from NeuroLifeNow, an app that collects the experiences of people with neurological conditions, show that in May and June 2021, showed that 1 in 5 of 252 respondents experienced delays to their care in the past eight weeks. Those who reported delays were more likely to require access to emergency support, and report feelings of anxiety and hopelessness⁴.
- With the addition of all pathways and independent providers, analysis by the Neurological Alliance⁵ showed that as of March 2021 over 10,000 people had been waiting more than a year for a neurology or neurosurgery appointment.
- Importantly, waiting to see a specialist or treatment is not static – symptoms will likely change and fluctuate. In some cases, for example in progressive neurological conditions, a person may deteriorate. With no diagnosis or explanation for the symptoms you are experiencing, for many people waiting for care is an extremely anxious and stressful time.
- Waiting for care may also mean limiting possible treatment options or reducing their effectiveness. For example, advanced drug therapies for Parkinson’s only have a short window during which they can be effective. Some people could already have lost their opportunity to have a life-changing therapy.
- Similarly, delays in diagnosis and subsequent delays in accessing treatments such as disease modifying therapies (DMTs) for conditions including MS can be the difference between slowing or even stopping the progression of the condition or further, more rapid deterioration.
- Some other treatments like botulinum toxin injections for dystonia and therapies for chronic migraine have also been cancelled, leaving people in pain and with more disabling

[with-Neurological-conditions-v3.pdf](#)

³ <https://www.england.nhs.uk/statistics/statistical-work-areas/rtt-waiting-times/rtt-data-2021-22/>

⁴ NeuroLifeNow, May-June 2021 report, available here: <https://neurolifenow.org/wp-content/uploads/2021/07/NLN-May-June-Results.pdf> Accessed on 3 September 2021.

⁵ <https://www.neural.org.uk/news/over-10000-people-waiting-over-a-year-for-neurological-services-neurological-alliance-analysis-reveals/>

symptoms. Waiting lists for these and other recurrent treatments are likely to take significantly longer to clear as patients are not seen and then discharged.

- The above examples are not isolated and given the nature of neurological conditions, many people with other neurological conditions may have seen their conditions significantly deteriorate since the onset of the pandemic. This will further compound the challenges associated with clearing the backlog in neurology with people requiring additional care and support.
- Concurrent to the steep increase in the number of people waiting for an appointment, referrals to neurology services dropped in many areas as services attempted to minimise referrals and prioritise the most urgent cases.
- Specialist Motor Neurone Disease centres saw a 30-50% reduction in referrals in 2020. Without access to specialist expertise patients cannot receive a confirmed diagnosis and begin accessing treatment and support for this complex and often rapidly progressive condition.
- Deep Brain Stimulation (DBS) – the main type of surgery suitable for some people with Parkinson’s – rates were down from an average of 240-260 new procedures per year to 135.
- A person with MS reported – ““I get that the pandemic caused unpredictable circumstances, but so does MS and other health conditions, and we should never be put on pause when it comes to our health. Being left with absolutely no support, care or communication when I needed it the most has left me with PTSD.”

Workforce

- The neurology workforce in the UK was insufficient and under resourced long before the pandemic but again, these pre-existing issues have been and continue to be exacerbated by the impact of the COVID-19 pandemic.
- The recent Association of British Neurologist (ABN) workforce survey⁶ notes that there are 1 per 91,175 (1.1 per 100,000) neurology consultants involved in patient care in the UK, one of the lowest rates of any European or high-income country. 35% of consultants are based in London & Southeast, although this remains well below the numbers in other high-income countries.
- Workforce shortages in neurology are similarly well known in other areas including specialist nurses, neuropsychiatrists, occupational therapists, physiotherapists, speech and language therapists. For example, 69% of people with MS live in areas where MS specialist nurses have caseloads more than the estimated sustainable caseload of 315 people with MS for each Whole Time Equivalent (WTE)⁷. Centralised data is not readily available across other neuroscience specialities.

⁶ https://cdn.ymaws.com/www.theabn.org/resource/collection/219B4A48-4D25-4726-97AA-0EB6090769BE/2020_ABN_Neurology_Workforce_Survey_2018-19_28_Jan_2020.pdf

- While already often running on a skeleton workforce, many of the specialist neurology workforce were redeployed to deal with the immediate pressures of the pandemic.
- There are also significant concerns about the impact of the pandemic on the health and wellbeing of healthcare professionals including those who care for people with neurological conditions.
- Supporting the psychological needs of the workforce, prioritising their safety, and addressing disruption to neurology training and education are critically important both in the immediate and longer term.
- Retaining existing staff must be prioritised alongside recruitment to reduce waiting times and improve patient care.
- Furthermore, changing models of care, such as enhanced triage, advice and guidance and the increasing use of remote consultations in outpatient care, are likely to change the education and training needs of many health and care professionals. They may also have variable impacts on their job satisfaction, mental and physical wellbeing. It is critical that health and care professionals across services for people with neurological conditions get the support they need to adapt to these changes as appropriate, as well as maintain their own wellbeing.

Learnings from the pandemic

- Ongoing work into some key areas of emerging or accelerated changes to service delivery is worthwhile and there are some learnings to be taken from the health services response to the pandemic into the future provision of services for people with neurological conditions.
- Areas of focus include remote consultations and patient initiated follow ups (PIFU). The focus of the system must not solely be on reducing outpatient waiting lists but more so on improving the quality and accessibility of services for people with neurological conditions.
- In relation to remote consultations more research is needed to evaluate their suitability and associated outcomes compared to traditional face-to-face assessments. Given questions around accessibility, suitability, and equality along with the critical consideration of patient choice, the approach to neurology outpatient appointments should not be digital by default.
- People with neurological conditions should be offered a choice of settings (both remote and face-to-face) where possible, given the fact that not all consultations and/or assessments can be carried out safely by telephone or video-conference according to our members. For virtual consultations, capacity must be in place to enable subsequent face-to-face appointments to take place where this is required.

⁷ Guy Hannan, Jo Sopala and Megan Roberts, 2018, MS Specialist Nursing in the UK 2018: Results from the 2018 MS Trust Nurse Mapping Survey, available at <https://mstrust.org.uk/sites/default/files/Nurse%20Mapping%202018%20WEB.pdf> Accessed on 3 September 2021

- Dystonia UK noted that access to remote services is welcome for people with dystonia, particularly those who might have more difficulty travelling or who live further away from their tertiary hospital. This choice, wherever possible, should be maintained.
- Another positive development is that the increased use of technology in the health service has allowed for MDTs and other specialist networks to connect with colleagues more easily across the country.
- The Neurological Alliance recently produced guidance informed by our members around the use of patient initiated follow ups (PIFU) in neurology services⁸.
- Key recommendations include identifying specific groups for whom PIFU is unlikely to be suitable, including children and young people and those with progressive conditions. It also highlights the vital role of shared decision making when considering changes to how services are delivered.
- Guidance of this type plays an important role in ensuring that any long-term changes to how services are provided have due consideration for the potential impact on people with neurological conditions.
- Any significant changes to the provision of neurological services must fully involve people with neurological conditions, healthcare professionals and VCSO in a meaningful and iterative way.
- Patient choice must also be maintained in areas such as remote consultations and PIFU. Due consideration should also be given to groups for whom these approaches are not likely to be suitable – including those with severe learning disabilities and some neurodevelopmental disorders.

Inequalities in care

- The unequal impacts of the COVID-19 pandemic have been well documented. The pandemic has revealed stark differences in the health of the population – those younger than 65 in the poorest 10% of areas in England were almost four times more likely to die from COVID-19 than those in wealthiest. Recovery needs to prioritise creating opportunities for good health⁹.
- A 2018 Public Health England report¹⁰ into deaths associated with neurological conditions in England found that the rates of premature epilepsy related mortality in the most deprived areas of England was three times higher than in the least deprived areas.

⁸ <https://www.neural.org.uk/wp-content/uploads/2021/06/Guidance-20210623-PIFU-principles-June-2021.pdf>

⁹ Suleman M, Sonthalia S, Webb C, Tinson A, Kane M, Bunbury S, Finch D, Bibby J. Unequal pandemic, fairer recovery: The COVID-19 impact inquiry report. The Health Foundation; 2021 (<https://doi.org/10.37829/HF-2021-HL12>)

¹⁰ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/683998

- Crucially, analysis from local Trusts indicate that some groups may be waiting for care for longer than others. For example, Calderdale and Huddersfield Foundation Trust analysis of waits for elective care indicated people with learning disabilities were disproportionately affected by lengthy waits for care, along with some people who have a minority ethnic background.
- We therefore urge the UK Government to adopt a coordinated, cross-departmental strategy to address health inequalities. This would include action to ensure specific groups do not experience disproportionate waits for care or worse outcomes.

Conclusions and recommendations

- The recent National Neurosciences Advisory Group (NNAG) report¹¹, 'Lessons learnt from the COVID-19 pandemic' provides robust recommendations that should be used to inform the government's response to addressing the impact of the pandemic on people with neurological conditions. We would urge the committee to engage with these recommendations in detail.
- In the short term, the Government must work with NHS England and NHS Improvement, commissioners, healthcare professionals, professional bodies and patient groups to ensure that services are restored to their pre-pandemic levels as soon as possible.
- In the longer term, NHS England and NHS Improvement should lead a national plan for neurology. The funded plan should seek to address longstanding and immediate issues identified across services and highlighted above including workforce shortages, lack of integration of mental health and neurology services and tackle longstanding health inequalities facing people with neurological conditions.
- We also fully support and endorse the recommendations made by Parkinson's UK in their response to this inquiry.
- For more information on this submission please contact our Policy and External Affairs Manager