

**Working together for a brighter future: Priorities in care for people affected by neurological conditions**  
**September 2022**

One in six people live with a neurological condition in England, and neurological conditions are the number one reason globally for disability. Despite this, low political attention and public policy leadership has typically been paid to the improvement of research, treatment and support for people affected by neurological conditions.

Many people living with and suspected of having a neurological condition face long waiting times, poor access to specialists and a lack of personalised care.<sup>1</sup> This has been further exacerbated by the impact of the COVID-19 pandemic.<sup>2</sup> As of June 2022, more than 198,000 people were waiting for an NHS neurology appointment and more than 57,000 people were waiting for neurosurgery. More than 7,900 (4%) have been waiting more than a year for their neurology appointment, and 39% have waited more than 18 weeks. 46% wait more than 18 weeks for neurosurgery, and 4,500 (8%) have waited more than a year.<sup>3</sup>

Our health and care workforce are under immense pressure. The shortage of specialists in almost all areas of neuroscience predates the pandemic. Warnings of safe staffing levels and the lack of specialist nurses in neurology, risking the safety of staff and patients, have been voiced for many years.<sup>4 5</sup> The pandemic has had a profound impact on the wellbeing, morale and mental health of the workforce and we are aware that many in the neuroscience workforce are considering a change of speciality or career as a result. Simultaneously recruitment is an issue. There are insufficient numbers of neuroscience trainees, and no profession will be able to recruit or upskill fast enough to overcome the demands facing neuroscience service

The NHS in England is both under pressure and undergoing significant structural and legislative reform. Yet opportunities to improve research, treatment and support for people affected by neurological conditions exist, despite unprecedented pressures.

The introduction of Integrated Care Systems (ICSs) represents an opportunity to better plan and deliver care on a population basis. The NHS England and NHS Improvement neuroscience transformation programme should provide a framework to improve the commissioning of specialised neuroscience services. New National Clinical Directors (NCDs) for neurology, neurosurgery and spinal surgery will provide vital clinical leadership at the heart of NHS England and NHS Improvement and will enable strategic alignment with both stroke and dementia.

In addition, new cross-Government strategies are being developed in both Acquired Brain Injury and ME, presenting important opportunities to improve the treatment, care and support, as well as research strategy, for these conditions.

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<sup>1</sup> Neurological Alliance 2019, *Neuro-Patience*. *Still waiting for improvements in treatment and care* <https://www.neural.org.uk/wp-content/uploads/2019/07/neuro-patience-2019-1.pdf> Accessed 3<sup>rd</sup> May 2022

<sup>2</sup> NNAG. 2021, *Lessons learnt from the COVID-19 pandemic. Priorities in care for people with neurological conditions after the pandemic*. <https://www.nnag.org.uk/lessons-learnt-from-covid19> Accessed 3<sup>rd</sup> May 2022

<sup>3</sup> The Patient Experience Library <https://www.patientlibrary.net/cgi-bin/library.cgi?page=WaitingLists> accessed 28th August 2022

<sup>4</sup> NNAG 2020, *Mental Health and Neuroscience Leaders Away Day Report* <https://www.nnag.org.uk/publications>

<sup>5</sup> Royal College of Nursing <https://www.rcn.org.uk/employment-and-pay/Safe-staffing>

We are therefore at a watershed moment for services for people affected by neurological conditions. In this context, and as NNAG prepares to wind down in light of the NCD appointments and a changing commissioning landscape, here we set out the overarching principles and priorities required to improve treatment, care and support for people with neurological conditions moving forward.

This vision has been drawn up by health professionals, academics, patient organisations and service leads within NHS England and NHS Improvement alongside evidence provided by people affected by neurological conditions.

## Principles

The following key principles serve as the foundation for improvements in care for people with neurological conditions. They are integral to addressing the current challenges facing the care of people with neurological conditions and for the future development of neurological services.

### 1. Co-production

People with lived experience of neurological conditions must be central to the support and services that will make a positive difference to their lives. As we transition into a new NHS it is essential that people with neurological conditions, and their families and carers, have their voices heard and are engaged as equal partners in local and national decision making. This includes engaging people with lived experience to co-produce pathways, design services and service improvements, and to evaluate at the earliest stages to achieve a person-centred care and capturing the unique needs of neuro patients to improve outcomes, experience of care, and increase efficiency for the system.

Critical to ensuring co-production in pathway and service design, development and evaluation will be:

- Ensuring people affected by neurological conditions and the voluntary sector play a central role in service improvement
- Integrated patient and public involvement in the implementation, review and evaluation of the neuro GIRFT recommendations, the NHS England and NHS Improvement neuroscience transformation programme and the optimum clinical care pathways across neurology and neurosurgery.
- Partnership working between NHS England and NHS Improvement and patient groups, including the Neurological Alliance, to facilitate co-production and include, and learn from, the diverse voices of people with neurological conditions

### 2. Collaboration

The wide range of conditions services and professionals involved in care for people with neurological conditions means that multidisciplinary collaboration is essential to capture, understand and reflect the many voices and perspectives in decisions to improve outcomes and experience of care. Since its inception in 2016, NNAG has been successful in fostering multi-disciplinary collaboration and engaging with the diverse voices and perspectives in the neurological community to provide thought leadership to the system. As neurological leadership and commissioning structures evolve it is essential that the steps already taken to improve collaboration are learnt from and built upon to improve the design and delivery of care, and to understand how resources can be directed for better value and outcomes.

Critical to ensuring collaboration will be:

- A strategic approach and mechanisms for engagement to ensure that national and local decision makers work in equal partnership with the broad spectrum of clinical professional groups involved in clinical pathways including - rehabilitation, neuropsychiatry, neuropsychology, pharmacy, specialist nursing, primary care, diagnostics, palliative care and social care teams.

- A strategic approach and mechanisms for engagement to ensure that national and local decision makers work in equal partnership with people with neurological conditions, families and carers, and patient organisations.

### **Priorities:**

The following areas focus on priorities for NHS England and NHS Improvement to continue to closely monitor the impact of the pandemic on people with neurological conditions and respond to existing and emerging areas for improvement in the next 3 years.

### **1. Ensuring optimal clinical care across the pathway**

Understanding what optimal clinical care looks like for people with neurological conditions and monitoring activity is essential to address unwarranted variation and support the improvement of services. There has been significant progress to address this in recent years, including the work of NNAG, GIRFT, RightCare and the neuroscience transformation programme. The GIRFT report recommends improving access, funding, resource and data infrastructure to ensure that the care pathways address unwarranted variation and improve patient outcomes and experience as well as efficiency savings for the system.<sup>6</sup> As we move forward it is essential that those learnings, pathways and recommendations, are implemented, monitored and reviewed to understand and improve outcomes and experience of care across the pathway.

In practice this will include:

- Publication and implementation of the optimal clinical pathways for neurology and neurosurgery developed by the NHS England and NHS Improvement neuroscience transformation programme and NNAG,
- Steps are taken to mitigate risks in neurology from changes to block contracts and tariffs to ensure the sustainability of services going forward. This should be done in partnership with service managers, health professionals and people with neurological conditions.
- Continued uptake and implementation of the recommendations from NNAG's "Lessons learnt from the COVID-19 pandemic" report at national and local level.
- A defined roadmap and evaluation framework for the implementation of the neurology GIRFT recommendations, developed in partnership with patient organisations, professional bodies and people with neurological conditions.
- Collaborative working between the wide range of national, regional and local partners delivering The National Diagnostics Programme board with the neurological community to deliver the objectives of the programme and improve pathways to diagnosis.
- Capacity in diagnostic & genomic services that reflects the rising demand for these services by people with neurological, and suspected neurological conditions
- An NHS England and NHS Improvement led rehabilitation strategy that addresses the complex needs of people with neurological conditions.
- Implementation of the recommendations from NNAG's mental health and neuroscience report at national and local level.
- A joint programme of work between patient organisations, health professional bodies and people with neurological conditions to better understand and address how patients with neurological conditions fall through the gaps in general mental health and wellbeing services.
- Clinical leadership for specialist neuropsychiatry services at Clinical Reference Group level, including a National Specialty Advisor post.

### **2. Action to reduce health inequalities**

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<sup>6</sup> NHS England 2021, *Neurology NHS GIRFT Programme National Speciality Report* <https://www.gettingitrightfirsttime.co.uk/medical-specialties/neurology/> accessed 3<sup>rd</sup> May 2022

We already know that people with neurological conditions face health inequalities. Indeed, GIRFT reports that the experience of patients with neurological disorders can vary significantly depending on where they live.<sup>7</sup> We also know that some inequalities have widened and become more apparent during the Covid-19 pandemic.<sup>8</sup> Despite this, neurological conditions are not one of the 5 Core20PLUS5 focus areas identified by NHS England and NHS Improvement. Action to reduce health inequalities must be central to all steps taken to improve neurological treatment, care and support to address this in the immediate and future.

In practice this will include:

- The improvement and alignment of health and care data sets and infrastructure to understand variation in access to care by protected characteristics. Where this is not possible, action should be taken to improve the quality of the data in order to allow for such analysis.
- Direct engagement with seldom heard groups living with neurological conditions to inform NHS services and programs in order to understand barriers to optimum care and to co-produce solutions.
- Development of an appropriate method to effectively commission the remote delivery of treatment and care across the clinical pathway that is co-produced, reduces the likelihood of widening digital inequalities and is rooted in driving good clinical outcomes.

### 3. Defining, measuring and improving outcomes

There is a need to build consensus and define the outcome measures that will bring about meaningful transformation in the design, delivery and commissioning of care and treatments for people with neurological conditions. NNAG's Neurology Outcomes Discussion<sup>9</sup>, led by the neurological community, represented an important step forward in the development of neurology outcome measures. Additionally, the GIRFT report recommends establishing mechanisms to better understand outpatient activity, and the creation of a neurology dashboard to better understand key metrics to support improvement.<sup>10</sup> It is critical that this momentum is maintained to improve how we understand, measure and improve care for people with neurological conditions, and that this is implemented nationally and locally.

In practice this will include:

- Implementation of the NNAG Neurology Outcomes Away Day recommendations and a collaborative approach to further developing outcome measures and expectation frameworks to improve care.
- The improvement of neurology data sets and data infrastructure, as identified by NIC and GIRFT, to improve understanding of activity in neurology, and future models of care.
- A clinically led pragmatic system of clinical classification of outpatient episodes which can be supported by NHS systems locally to allow for better service planning, improvements and the measurement of outcomes.

### 4. Supporting the workforce

Staff shortages in neuro have been recognised for many years,<sup>11, 12, 13</sup> and the COVID-19 pandemic has increased the backlog of patient care they must manage.<sup>14</sup> The GIRFT neurology report recommends that the workforce is developed to improve the distribution of neurologists and allied health professionals, and to

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<sup>7</sup> *ibid.*

<sup>8</sup> NNAG 2021 *op cit*

<sup>9</sup> National Neurosciences Advisory Group 2021, *Neurology Outcomes Discussion* <https://www.nnag.org.uk/outcomes> Accessed 3<sup>rd</sup> May 2022

<sup>10</sup> NHS GIRFT 2021 *op cit*

<sup>11</sup> Royal College of Physicians. 2011. *Neurology services not meeting patients' needs*. <https://www.rcplondon.ac.uk/news/neurology-services-not-meeting-patients-needs> Accessed 3<sup>rd</sup> May 2022

<sup>12</sup> Langton Hewer, R. 2013. *Neurology on the move?* *Clinical Medicine*, 13(5), pp. 440-2.

<sup>13</sup> Orlando, L. 2001. *Shortage of UK neurologists*. *Trends in Neurosciences*, 24(9), p. 504.

<sup>14</sup> NNAG 2021 *op. cit*

train advanced practitioners including specialist nurses and physician associates, which would result in better services and ensure safety for patients. As the need for neurological services increases it is essential that we have a skilled workforce to meet the demands of this growing and ageing population. Supporting the psychological needs of the workforce, prioritising their safety and the safety of patients, as well as addressing disruption to neurology training and education during the pandemic years, is now of critical importance.

In practice this will include:

- Formal mapping and review of the workforce across all brain (and spine and peripheral nervous system) conditions, both in terms of numbers and (common initial) training curricula (preferably starting at undergraduate level), to form a more coherent and attractive multi-disciplinary “brain-force” fit for the current and future decades.
- The bridges that exist between Neurology/Neurosurgery/Neurophysiology and Stroke and Dementia and Psychiatry and General Medicine/Elderly Care and Rehabilitation become the foundational sub-structure from which medical and non-medical staff can evolve a superstructure with sub-specialties that retain generalist skills.
- NHS England and NHS Improvement and local Integrated Care Boards work with health professional bodies to define and monitor safe staffing requirements for current and future models of care in neuroscience.
- Interventions, including “wellbeing hubs” are made available and accessible to the workforce beyond the pandemic.
- Routine workforce data collection and supporting infrastructure to allow for a model that, when compared with trends in the demand for care, can allow for the workforce challenge to be accurately assessed, understood and supports workforce planning
- Inter-disciplinary credentialling programmes that enable more workforce flexibility are rolled out.
- Opportunities to train advanced practitioners, including specialist nurses, are identified in new and emerging models of outpatient care to increase efficiency to the system.
- The neurological and genomics workforce is expanded and upskilled to account for the impact of genomics in neurology.

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**For more details on NNAG’s work please visit: [www.nnag.org.uk](http://www.nnag.org.uk)**