

Health Bill Call for Evidence: Submission from The Neurological Alliance

1. Executive Summary

- 1.1. The Neurological Alliance has significant concerns regarding the implications of the Health Bill for people affected by neurological conditions. One in six people live with a neurological condition¹, a condition which affects your brain, spinal cord, and/or nervous system.
- 1.2. For people affected by neurological conditions, success will be determined not by organisational reform itself, but by whether it delivers clearer accountability, stronger clinical leadership and more joined-up care across organisational boundaries.
- 1.3. Neurological services cross every organisational boundary the Bill touches: neighbourhood, Integrated Care Board (ICB), regional and national. They are therefore a critical test of whether the reforms deliver in practice.
- 1.4. The Alliance's concerns about the Bill fall under six themes:
 - 1.4.1. Theme one: Accountability and Oversight (Clauses 1, 2, 12, 20) - The Bill provides limited clarity about how accountability will operate across pathways that span neighbourhood, ICB, regional and national footprints.
 - 1.4.2. Theme two: Clinical Leadership (Clauses 1, 2, 8, 12) - The Bill provides limited assurance regarding the future of national clinical leadership, specialist commissioning expertise and clinical advisory structures.
 - 1.4.3. Theme three: Patient voice (Clause 15, 64) - The Alliance believes stronger safeguards are needed to ensure meaningful involvement of people affected by neurological conditions and the voluntary sector in service planning, commissioning and evaluation.
 - 1.4.4. Theme four: Neighbourhood health (Clause 24) - Neighbourhood Health Plans must connect to specialist services, or people with complex, lifelong neurological conditions will fall through the gaps.
 - 1.4.5. Theme five: Workforce - The success of the reforms will depend on the availability of a suitably skilled workforce. Neurological services already face significant workforce shortages and variation in access to specialist professionals.
 - 1.4.6. Theme six: Digital and Information Sharing (Clause 47) - The Alliance supports efforts to improve information sharing and care coordination. However, successful implementation will depend on public trust, accessibility,

interoperability and meaningful involvement of patients in decisions about how information is used.

2. Introduction

- 2.1. The Neurological Alliance is England's leading coalition for people affected by neurological conditions, bringing together more than 100 organisations, including charities, professional bodies and patient groups.
- 2.2. Neurological conditions include common conditions such as migraine, epilepsy and Parkinson's disease, as well as rarer and highly complex neurological conditions. Together, neurological conditions are the leading cause of disability worldwideⁱⁱ and place a substantial burden on health and care servicesⁱⁱⁱ. Together they affect millions of people and have wide-ranging impacts on independence, employment, education and quality of life.
- 2.3. The scale of the challenge is growing. Globally, the number of people living with neurological conditions is projected to increase by 22% between 2021 and 2050^{iv}.
- 2.4. The Alliance's evidence is informed by My Neuro Survey^v, the largest patient experience survey of neurological conditions in England, alongside ongoing engagement with people affected by neurological conditions, healthcare professionals, researchers and voluntary sector organisations.
- 2.5. These experiences are reflected in wider system performance. Neurology waiting times remain among the longest in the NHS. In April 2026, only 60.2% of people waiting for a neurology appointment were seen within 18 weeks, below the NHS elective care plan target of 65% by April 2026^{vi}.

3. Theme One: Accountability and Oversight, Clauses 1 and 2 (Abolition of NHS England); Clause 12 (Commissioning Functions); Clause 20 (Performance Assessments)

- 3.1. The Alliance supports the Government's ambition to improve decision-making at every level of the system. Our central concern is that the Bill does not clearly establish who is accountable when care crosses neighbourhood, ICB, regional and national boundaries.
- 3.2. My Neuro Survey consistently highlights the impact when coordination between services breaks down. People affected by neurological conditions report repeating their story multiple times, difficulties navigating services and challenges accessing support when their needs change. The consequences of fragmented pathways are visible across neurological services. This is particularly challenging for people whose care spans multiple specialties, where no one specialty takes overall ownership of their care, or where they are under a specialty that does not reflect their most significant symptoms or needs.
- 3.3. The Government's own impact assessments^{vii} acknowledge risks associated with organisational transition, including disruption and loss of expertise. These risks are particularly significant for neurological services, which rely on coordinated care across multiple parts of the health system.

- 3.4. The Bill enables changes to specialised commissioning through secondary legislation. However, the services that will remain the responsibility of the Secretary of State and those that may transfer to Integrated Care Boards are not specified in the Bill.
- 3.5. The Government's Equality Impact Assessment^{viii} acknowledges that it is not currently possible to assess the impact of these changes because the affected specialised services will be determined through future regulations.
- 3.6. This is a significant issue for neurological services, where care frequently spans neighbourhood, community, regional and national services. Changes to commissioning responsibilities could have important implications for accountability, care coordination and equitable access.
- 3.7. The Alliance is concerned that Parliament is being asked to consider the framework for reform before it is possible to assess the implications of future commissioning arrangements for specialised neurological services.
- 3.8. The Bill provides limited clarity regarding:
- 3.8.1. how accountability will operate across pathways that span neighbourhood, ICB, regional and national footprints;
 - 3.8.2. how national standards will be maintained where responsibilities are shared across different parts of the system;
 - 3.8.3. how variation in access and outcomes will be identified, monitored and addressed; and
 - 3.8.4. how patients, clinicians and Parliament will assess whether the reforms are improving outcomes.
- 3.9. The Alliance asks the Committee to consider:
- 3.9.1. requiring an independent impact assessment to be published before any transfer of specialised commissioning responsibilities or accountability takes effect.
 - 3.9.2. requiring any future changes to specialised commissioning responsibilities to be accompanied by public consultation and a published impact assessment;
 - 3.9.3. requiring the Secretary of State to publish annual information on specialised service performance, including waiting times, outcomes, workforce indicators and implementation of national service specifications and commissioning policies;
 - 3.9.4. Require performance assessments of ICBs to include implementation of national service specifications, compliance with commissioning policies and variation in access and outcomes.
 - 3.9.5. Require annual public reporting on specialised service performance, including waiting times, outcomes, workforce indicators and implementation of national service specifications, at both ICB and regional level.

4. Theme Two: Clinical Leadership and Expertise (Clauses 1, 2, 8 and 12)

- 4.1. The Bill team have indicated that the Bill aims to improve effective decision-making across the system. High-quality decision-making depends upon access to appropriate clinical expertise and leadership. The Bill contains provisions relating to patient

involvement but no equivalent provisions regarding clinical involvement in decision-making.

- 4.2. Neurological services depend upon specialist expertise that is often organised regionally or nationally. The National Clinical Directors for Neurology, Neurosurgery and Rehabilitation have played a critical role in providing strategic clinical leadership across the NHS. For example, the NCD for Neurology role has helped establish clear priorities for neurological service transformation, supported the development of national standards through the Adult Neurology Service Specification, driven the spread of best practice across systems, advised on specialised commissioning, and ensured a strong neurological voice within national policy and decision-making. For the one in six people with neurological conditions, this leadership has been invaluable in promoting more consistent, equitable and clinically informed care.
- 4.3. Clinical Reference Groups^{ix} (CRG) provide a unique and valuable structure through which clinicians, commissioners, patient representatives and the voluntary sector can collectively shape national policy and commissioning decisions for neurological services. The Adult Neurology CRG, for example, has played a central role in developing the Adult Neurology Service Specification^x, advising on commissioning policies, identifying opportunities to improve quality and reduce variation, and ensuring that decisions affecting neurological services are informed by clinical expertise and lived experience. Its work has been fundamental to advancing more consistent, evidence-based care for the one in six people living with neurological conditions in England.
- 4.4. The National Clinical Director for Neurology and Clinical Reference Groups have provided invaluable leadership in driving service improvement, shaping national standards and ensuring neurological expertise informs policy and commissioning decisions. The Bill provides little assurance that these functions will be preserved.

4.5. The Alliance asks the Committee to consider mechanisms that ensure:

- 4.5.1. Clinical expertise is embedded within the commissioning and oversight of specialised services, regardless of whether commissioning responsibility sits with the Secretary of State, an Integrated Care Board or another delegated body.
- 4.5.2. National clinical leadership for neurological services is maintained to provide strategic oversight, champion service improvement, advise Ministers and commissioners, and support the consistent implementation of national standards.
- 4.5.3. National clinical advisory structures, including Clinical Reference Groups or equivalent multidisciplinary arrangements, are maintained to ensure commissioning decisions, service specifications and national policy continue to be informed by clinical expertise, patient experience and voluntary sector input.
- 4.5.4. National clinical leadership and advisory arrangements are transparent, adequately resourced and have clearly defined roles, responsibilities and accountability within the new NHS architecture.

5. Theme Three: Patient Voice and Involvement Clause 15 (Secretary of State duty to involve service users)

- 5.1. The Alliance recognises the duty in Clause 15 requiring the Secretary of State to make arrangements for patient and public involvement in commissioning. We support the principle that people affected by neurological conditions should shape the services they use.
- 5.2. As commissioning responsibilities become more distributed across neighbourhood, system, regional and national levels, it becomes increasingly important that people affected by neurological conditions are able to influence decisions consistently, regardless of which organisation is exercising commissioning responsibilities.
- 5.3. My Neuro Survey, the largest patient experience survey of neurological conditions in England, consistently demonstrates the value of listening to people affected by neurological conditions. It provides vital insight into the quality, coordination and accessibility of services, highlighting issues that are not always captured through routine performance data. Patient experience should be recognised as an essential source of evidence to inform service planning, improvement and evaluation.
- 5.4. The Alliance recognises the new statutory duty in Clause 15. However, the Bill provides limited clarity regarding how these arrangements will operate in practice, particularly for services that span multiple Integrated Care Boards and national commissioning arrangements.
- 5.5. Existing mechanisms, including Patient and Public Voice (PPV) representatives within Clinical Reference Groups, have enabled people with lived experience to influence specialised services at a national level. The Bill does not explain how equivalent opportunities for engagement will be maintained following the transfer of NHS England's functions.
- 5.6. The proposed abolition of Healthwatch England and Local Healthwatch organisations makes this more urgent. Independent patient voice must be strengthened, not weakened, by the reforms. Parliament should be assured that the new arrangements will strengthen, rather than weaken, independent patient involvement.

5.7. The Alliance asks the Committee to consider mechanisms that ensure:

- 5.7.1. Patient and public involvement is embedded within the planning, commissioning and evaluation of specialised services, regardless of whether responsibility rests with the Secretary of State, an ICB or another delegated body.
- 5.7.2. National arrangements are established to support consistent patient and public involvement in specialised services following the abolition of NHS England.
- 5.7.3. Commissioners demonstrate how the views of people affected by neurological conditions, carers and representative organisations have informed commissioning decisions, service redesign and service reconfiguration.
- 5.7.4. Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are routinely collected, published and used to support transparency, accountability and continuous improvement.

5.7.5. The Secretary of State reports on how the arrangements established under Clause 15 are supporting meaningful patient involvement and improving commissioning decisions.

6. Theme Four: Neighbourhood Health (Clause 24)

- 6.1. The Alliance supports the development of neighbourhood health services. For people affected by neurological conditions, this presents an opportunity to move from fragmented, reactive services towards care that is proactive, coordinated and easier to navigate.
- 6.2. Clause 24 of the Bill replaces Joint Local Health and Wellbeing Strategies with Neighbourhood Health Plans, requiring local authorities and Integrated Care Boards to prepare plans describing how the health and care needs of their populations will be met. The Alliance welcomes this new statutory focus on neighbourhood health.
- 6.3. Neurological conditions are not yet recognised as a national priority cohort within neighbourhood health. Without explicit consideration, there is a risk that people affected by neurological conditions will be overlooked despite representing one of the largest groups of people living with long-term conditions.
- 6.4. The Alliance's 'Vision for Neuro Neighbourhood Health' demonstrates that neighbourhood care should not be viewed as an alternative to specialist care, but as specialist-informed care delivered closer to home. This depends upon clear and continuous links between neighbourhood teams and specialist neuroscience services through shared care arrangements, multidisciplinary working, virtual MDTs, advice and guidance, outreach and Integrated Neurology Systems.
- 6.5. People affected by neurological conditions frequently experience anxiety, depression, cognitive change and other neuropsychiatric symptoms alongside their neurological condition. My Neuro Survey found that 60% of respondents who needed neuropsychology or neuropsychiatry were unable to access it, despite well-documented higher rates of mental health need across many neurological conditions. Neighbourhood Health Plans should therefore demonstrate how neurological, mental health and rehabilitation services will work together to provide coordinated, person-centred care.
- 6.6. Without these connections, there is a risk that Neighbourhood Health Plans reinforce organisational boundaries rather than overcoming them, resulting in fragmented pathways for people whose care cannot be delivered within a single neighbourhood or Integrated Care Board.

6.7. The Alliance asks the Committee to consider mechanisms that ensure:

- 6.7.1. Neighbourhood Health Plans demonstrate how they will meet the needs of people living with complex, long-term neurological conditions whose care spans neighbourhood, community, specialist and highly specialised services.
- 6.7.2. Neighbourhood Health Plans demonstrate how neighbourhood services will work with specialist neurological services, Integrated Neurology Systems, regional clinical networks and voluntary sector partners to deliver coordinated, person-centred care.

- 6.7.3. Guidance issued by the Secretary of State under Clause 24 includes clear expectations that Neighbourhood Health Plans support integrated pathways for people with complex conditions, including access to specialist expertise, rehabilitation, neuropsychology, neuropsychiatry and care coordination.
- 6.7.4. People affected by neurological conditions, carers, clinicians and representative organisations are meaningfully involved in the development, implementation and review of Neighbourhood Health Plans.
- 6.7.5. Integrated Care Boards and local authorities publish how their Neighbourhood Health Plans will reduce unwarranted variation, improve care coordination and support better outcomes for people affected by neurological conditions.

7. Theme Five: Workforce

- 7.1. The Bill proposes significant organisational change, including the abolition of NHS England and the transfer of functions to the Department of Health and Social Care and Integrated Care Boards. Delivering these reforms, alongside the Government's ambitions for neighbourhood health, will depend upon retaining and strengthening the specialist workforce and expertise needed to commission, plan and deliver neurological services.
- 7.2. Workforce shortages already represent one of the most significant barriers to improving neurological services. Shortages exist across multiple professions, including consultant neurologists, specialist nurses, psychologists, rehabilitation professionals, care coordinators and allied health professionals. These shortages contribute to long waiting times, inequitable access to care and variation in outcomes.
- 7.3. The Government's own impact assessment^{xi} recognises that the transition created by the Bill carries risks, including organisational disruption and the potential loss of expertise. For neurological services, these risks extend beyond the clinical workforce to include specialist commissioning expertise, clinical leadership and institutional knowledge that support the planning and delivery of services across local, regional and national footprints.
- 7.4. Without clear safeguards, there is a risk that workforce capacity is weakened rather than strengthened. The Alliance is concerned that the Bill provides limited assurance about how expertise will be retained throughout implementation, or how the workforce implications of the reforms will be monitored and reported.

- 7.5. The Alliance asks the Committee to consider mechanisms that ensure:
- 7.5.1. Specialist commissioning expertise and national clinical leadership are retained throughout the transition from NHS England.
- 7.5.2. The workforce implications of transferring NHS England's functions are assessed and reported publicly, including the impact on specialist services.
- 7.5.3. Implementation of the Bill is supported by sufficient workforce capacity across specialist, community and neighbourhood neurological services.
- 7.5.4. The Secretary of State reports on the impact of the reforms on workforce capacity, capability and access to specialist expertise as part of wider monitoring of the Bill's implementation.

8. Theme Six: Digital Transformation and the Single Patient Record, Clause 47 (Information sharing)

- 8.1. The Alliance supports ambitions to improve information sharing and care coordination. Better access to accurate, timely information has the potential to improve care coordination, reduce duplication and support more integrated care for people affected by neurological conditions.
- 8.2. People affected by neurological conditions frequently receive care from multiple providers over many years, including primary care, social care, community services, mental health services, rehabilitation services, specialist neuroscience centres and highly specialised services. My Neuro Survey consistently highlights the challenges people experience when information is not shared effectively between services, including having to repeat their medical history and navigate fragmented pathways.
- 8.3. The powers provided by Clause 47 could make an important contribution to addressing these challenges. However, the benefits for people affected by neurological conditions will depend upon consistent implementation across organisational and commissioning boundaries, rather than simply the adoption of new digital systems.
- 8.4. The Bill provides limited assurance regarding how the new information-sharing arrangements will support people whose care routinely spans neighbourhood, Integrated Care Board, regional and national services. The Alliance believes implementation should explicitly support continuity of care across these boundaries and enable professionals to access the information they need to provide safe, coordinated care.
- 8.5. Successful implementation will depend on information being shared seamlessly across NHS organisations and social care, with systems that are interoperable, accessible to people with neurological conditions, including those with cognitive, communication and sensory impairments, and trusted by the public through strong information governance.
- 8.6. It will also be important to ensure that carers, where appropriate and with the individual's consent, can access and contribute relevant information to support coordinated care.
- 8.7. Finally, people affected by neurological conditions and their representative organisations should be meaningfully involved in the design, implementation and evaluation of new information-sharing arrangements to ensure they reflect the realities of living with complex, lifelong conditions.

8.8. The Alliance asks the Committee to consider mechanisms that ensure:

- 8.8.1. Guidance and implementation arrangements made under Clause 47 explicitly address the needs of people with complex, long-term conditions whose care routinely spans neighbourhood, community, specialist and highly specialised services, as well as multiple commissioning arrangements.

- 8.8.2. Information-sharing arrangements introduced under Clause 47 support safe, coordinated and continuous care across organisational and geographical boundaries, reducing fragmentation and unnecessary duplication for people affected by neurological conditions.
- 8.8.3. People living with neurological conditions, carers and representative organisations are meaningfully involved in the development, implementation and evaluation of information-sharing arrangements established under Clause 47, ensuring they are accessible, trusted and responsive to users' needs.
- 8.8.4. The Secretary of State publishes an annual assessment of the implementation of Clause 47, including its impact on care coordination, patient experience, health inequalities, accessibility and outcomes for people with complex and rare conditions.
- 8.8.5. Information-sharing arrangements support appropriate information sharing with carers, where consent has been given or where otherwise permitted by law, recognising the essential role that many carers play in coordinating care for people living with neurological conditions.

9. Next steps

- 9.1. The Neurological Alliance welcomes the opportunity to make this submission to the Committee at an early stage in the passage of the Health Bill. We will now be undertaking further consultation with our members to discuss potential amendments in more detail. We look forward to keeping the Committee updated on the progress of this work. If you would like to get in touch, please contact us at georgina.carr@neural.org.uk

ⁱ The Neurological Alliance (2019) Neuro Numbers Available here: <https://www.neural.org.uk/wp-content/uploads/2021/04/neuro-numbers-2019-1.pdf>

ⁱⁱ Steinmetz J, Seher K, Schiess N et al. (2024) Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021 The Lancet Neurology, 2024; 23, 344–381 [https://www.thelancet.com/journals/lanneur/article/PIIS1474-4422\(24\)00038-3/fulltext](https://www.thelancet.com/journals/lanneur/article/PIIS1474-4422(24)00038-3/fulltext)

ⁱⁱⁱ The Economist Impact Unit (2024) The value of action: mitigating the impact of neurological disorders in the United Kingdom <https://impact.economist.com/health-society/value-action-mitigating-impact-neurological-disorders-united-kingdom>

^{iv} Lei, J & Gillespie, K (2024) Projected Global Burden of Brain Disorders Through 2050. Neurology Journal <https://www.neurology.org/doi/10.1212/WNL.0000000000205009>

^v The Neurological Alliance (2025) Act now for the 1 in 6: My Neuro Survey results <https://www.neural.org.uk/act-now-for-the-1-in-6/>

^{vi} NHS England (2026) Referral to Treatment (RTT) Waiting Times <https://www.england.nhs.uk/statistics/statistical-work-areas/rtt-waiting-times/>

^{vii} Department of Health and Social Care (2026) Final stage impact assessment, Health Bill: Abolishing NHS England https://publications.parliament.uk/pa/bills/cbill/59-02/0009/ia_Abolishing_NHS_England.pdf

^{viii} Department of Health and Social Care (2026) Health Bill: ICBs as strategic commissioners – equality impact assessment. Available at: <https://www.gov.uk/government/publications/health-bill-icbs-as-strategic-commissioners-equality-impact-assessment/health-bill-icbs-as-strategic-commissioners-equality-impact-assessment>

^{ix} NHS England (2026) National Programmes of Care and Clinical Reference Groups, <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-d/neurology/>

^x NHS England (2025) Adult Neurology Service Specification (D04/S/a – 250801) <https://www.england.nhs.uk/wp-content/uploads/2025/08/specialised-neurology-services-adults-service-specification-august-2025.pdf>

^{xi} Department of Health and Social Care (2026) Final stage impact assessment, Health Bill: Abolishing NHS England https://publications.parliament.uk/pa/bills/cbill/59-02/0009/ia_Abolishing_NHS_England.pdf