

Health & Social Care Committee Inquiry - Integrated Care Systems: autonomy and accountability - response from the Neurological Alliance

About the Neurological Alliance

The Neurological Alliance is a coalition of more than 80 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 known neurological conditions ranging from comparatively common conditions such as migraine and epilepsy to rare conditions such as the ataxias and Guillain-Barre syndrome.

1 in 6 of us live with a neurological condition, and many more are impacted as families, friends and carers.

Neurological conditions 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. Some conditions are terminal and/or life-threatening.

Summary of response

This response highlights the need to ensure that the move towards Integrated Care Systems does not exacerbate unwarranted variation in access to or quality of services for people with neurological conditions. It also makes recommendations and highlights best practice examples around how ICSs could deliver joined up health and care services to best meet the needs of people with neurological conditions.

There is a specific focus on the following themes, supported by case study examples where applicable:

- Recommendations to prevent unwarranted variation and address health inequalities in neuroscience services
- The importance of co-production, co-design and involvement of people affected by neurological conditions and the VSCE
- The need to clarify multi-ICB working arrangements
- Improvements to data and evidence
- The centrality of service specifications, optimum pathways, clinical policies and Clinical Reference Group (CRG)
- The need for a Neuro Taskforce to provide political leadership and coordination

We would like to thank the Committee for the opportunity to submit to this important inquiry.

Our core recommendations

As set out in the recent NHS England and NHS Improvement "[Roadmap for integrating specialised services within Integrated Care Systems](#)", responsibility for the commissioning, planning and leadership of many key services for people with neurological conditions will be delegated to Integrated Care Boards (ICBs) from April 2023.

The focus of Integrated Care Systems (ICSs) on health inequalities, collaboration, integration and population represents an important opportunity for improvements to care. However, without clear national standards and outcomes, strong data and insight and robust mechanisms to support patient and clinical leadership, we are concerned that this shift in responsibility could exacerbate existing unwarranted variation in services.

Significant regional variation in the structure and delivery of care exists across England. The recent Getting it Right First Time (GIRFT) in Neurology [report](#), for example, found marked variation in access to specialist nurses between sites. For some people, regular treatments, such as disease modifying treatments (DMTs) for multiple sclerosis (MS) or botulinum toxin for dystonia, were available at their local hospital while in other areas these were only available at specialist neuroscience centres necessitating significant travel. In some areas clinics for common disorders such as epilepsy, MS and Parkinson's were available at local hospitals, in others only at neuroscience centres.

Similar variation is also evident in relation to experience of treatment and care reported through [My Neuro Survey](#). More than 8,500 adults, children and young people affected by a neurological condition responded to the survey across the UK. More than a third (36%) of respondents reported not being signposted or referred to support for their mental wellbeing in the last three years despite feeling that such support would be beneficial. Those living in areas of higher deprivation were more likely to report experiencing delays to their care. Women were more likely than men to report waiting longer before being diagnosed by a specialist.

With such variation in mind, our recent 'Together for the 1 in 6' policy report set out a series of recommendations which we believe would support a permissive framework for ICS' and help to address inequalities in care:

1. Every Integrated Care Board (ICB) works with the neurological community in their area to map current service provision for people affected by neurological conditions and set out plans to address shortcomings in care.
2. Every ICB has a clinical and patient lead for services for people affected by neurological conditions in their area.
3. Every Integrated Care Partnership (ICP) includes people affected by neurological conditions and/or a representative from the neurological VSCE sector.

4. Trusts, provider collaboratives and ICBs work together to implement common features of neuroscience pathways, including named care coordinators, access to mental wellbeing support and timely access to specialists, access to clinical research alongside other best practice recommendations included in:
 - National Neurosciences Advisory Group (NNAG) and neuroscience transformation programme optimum clinical pathways
 - NHS RightCare Toolkits & Pathways on progressive neurological conditions, headache and migraine and epilepsy
 - Relevant NICE Guidance and Quality Standards
5. ICBs and NHS Trusts work with the voluntary sector and local people to understand local need and implement coordinated and integrated care for people affected by neurological conditions.

We encourage the Committee to engage with and support these recommendations as part of this inquiry.

The importance of co-production, co-design and involvement of people affected by neurological conditions and the VSCE

Involving people affected by neurological conditions in key ICS bodies, boards and forums is key to delivering effective and efficient services, as well as meeting our shared goal of personalised care.

We strongly believe organisations within and between ICS' should engage in strategic co-production wherever it is possible and appropriate to do so - this is a way of working at a strategic level that enables decisions to be made with people with lived experience to influence policy, service design, delivery, evaluation and resource allocation.

People affected by neurological conditions involved in service development and delivery must be supported to undertake their role, are clear on the expectations of it and able to tap into the insight and experiences of a wide range of neurological conditions.

In addition, every effort must be made to listen and engage with as diverse a range of people as possible. In particular, under-represented groups, such as those living with rare neurological conditions, LGBTQIA+ groups and people of colour must be actively encouraged and supported to take part in service improvement initiatives.

The Health and Care Act 2022 was a missed opportunity to increase patient voice and patient involvement. Previous requirements on Clinical Commissioning Groups (CCGs) to involve patients in decision-making were transferred to ICSs in the Act. However, with experiences from our member organisations supporting people with neurological conditions to campaign to improve services in their local area, we know these requirements are too often ignored.

We are supportive of calls made by National Voices in their [submission](#) to the Health and Social Care Select Committee inquiry into the Health and Care White Paper, which proposes:

- A clear duty to collaborate with people, communities and their organisations - increasing accountability, transparency and engagement
- All ICSs should be obliged to design and report on mechanisms that enable engagement at System level
- That these changes must also be reflected at all ICS levels - System (ICB and ICP), Place and Neighbourhood.

We urge the Committee to support these recommendations and encourage the Government, in collaboration with the VCSE sector, to make the necessary regulatory and/or legislative changes to strengthen ICS responsibilities to meaningfully engage



with the VCSE sector and people with lived experience at all levels of Integrated Care Systems - System, Place and Neighbourhood.

Case study: The South London and Surrey Neuroscience Network - Neuro Voices

The South West London Neurosciences Network is a well-established network with a track record of working collaboratively across organisations and successfully transforming neurological services across the region. It is an ICS-based clinical network with multiprofessional leadership and membership from community, primary, secondary and tertiary care. The network wanted to ensure that patient views, lived experience and expertise were at the centre of all their work.

The network secured funding from the SW London ICS to co-design a public and patient involvement (PPI) strategy which reflects the diversity and complexity of the needs of people living with neurological conditions and their families, working in partnership with neurosciences staff at all levels in the system.

“It is vitally important for us as people with neurological conditions and people caring for those with neurological conditions are working hand in hand with people that run neurology services in our local area. We have seen so many times that services have been changed with the intention of improving them with little or no involvement from people that use those services and time and time again we find that the change is not what the people that use the services want or need. Through the NeuroVoices project we have all come together to decide how we would like to work together and solve problems together by creating a shared vision, mission and priorities for the next 2 years. We have had buy in from the highest points of the ICS which have meant that we all feel that we have the power to achieve what we’re setting out to achieve” Scott Ballard-Ridley, Neuro Voices Network lead

They hope that the South West London Neuro Voices Network will act as a model and blueprint for patient engagement across the system. 80 people affected by neurological

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conditions are regularly involved in the network, with opportunities to expand this as the network develops.

By jointly harnessing the expertise of patients and staff into their transformation plans, the following benefits have been realised:

- better and more appropriate targeting of resources across the whole pathway
- a clearer system focus on patient experience and outcomes rather than just routinely collected activity metrics
- understanding of barriers to access, thus helping us address health inequalities
- enabling more effective self-management programmes

The need to clarify multi-ICB working arrangements

We are particularly concerned that services for low prevalence or rare neurological conditions, and/or where services are scarce (such as services for Functional Neurological Disorder) are unlikely to be a priority for ICBs, and are therefore particularly vulnerable.