

UK Neuro Forum: inaugural meeting - 10 March 2025

Published 10 March 2025

Contents

Attendees	 2
Meeting minutes summary.	 2

Attendees

- Minister Ashley Dalton, Parliamentary Under Secretary of State for Public Health and Prevention (to open)
- Community Health Deputy Director, the Department of Health and Social Care (DHSC) (Chair)
- representatives from:
 - DHSC
 - NHS England
 - devolved governments (policy and clinical leads)
 - neurological alliances of all 4 UK nations
 - British Paediatric Neurology Association
 - Association of British Neurologists

Meeting minutes summary

1. Welcome and introductions

Minister Dalton opened the forum, thanking members for their engagement and paying tribute to charities that support people with neurological conditions. The minister set out stark statistics on neurological conditions, and key challenges faced by the NHS, neurology services and their patients.

She reaffirmed the government's commitment to improve care for people with long-term conditions, including neurological conditions, reflected on investment in research, the upcoming 10 Year Health Plan and ways in which the new forum could help bring change to patients.

2. Overview of challenges and strategic priorities for each of the 4 nations, neurosurgery and paediatrics

The forum members discussed key challenges across all 4 nations. These included variation in provision and access, long waiting lists, challenges within specialised care provision, access to new treatments, the need for better person-centred care and clear

planning to ensure greater equity. Workforce was raised as a particular concern, especially for certain roles (such as specialist nurses), across both inpatient and outpatient services.

Workforce (including staff numbers, distribution, speciality training, sub-speciality credentialing, data improvements), transformative therapies, harnessing digital opportunities around streamlining care, translating research into practice, and cross-border care were considered as key areas that the forum should focus on.

In terms of paediatric services, access to timely care, appropriate training of professionals, the need to develop specialised services and the management of transition from children and young people's services to adult services were raised as particular challenges. Greater support for genomic medicine delivery, more investment in research and paediatric neurosciences and greater equity of access is required.

Regarding neurosurgery, issues highlighted included operating theatre capacity, lack of dedicated emergency theatre access, inpatient bed availability, day of surgery resources, barriers to discharge, difficulty implementing repatriation policies, limited access to access to technology, access to rehabilitation, future of neurosurgery and safe neurosurgery initiatives.

Members summarised key strategic priorities, outlining ongoing and planned work:

- in England, this includes pieces of work such as the 10 Year Health Plan, Long-Term Workforce Plan, the Elective Reform Plan, NHS England's Neurology Transformation Programme, Getting It Right First Time Programme, and the work of the 8 regional networks for neurosurgery, as well as condition-specific initiatives
- in Northern Ireland, a regional review of services has identified 4 overarching priorities for neurology: a person-centred service, developing additional workforce capacity, addressing the identified gaps and using current resources more effectively
- in Scotland, colleagues noted the <u>Neurological care and support: framework for action</u>
 <u>2020 to 2025</u>, work on a long-term conditions strategy, ensuring a consistent approach
 to adopting innovative practice, and improvement of NHS information on neurological
 conditions
- in Wales, colleagues noted the work of the Neurological Conditions Network on setting direction, looking at national standards and trying to reduce variation, as well as the completed workforce survey and the development of a data dashboard

3. Summary of priorities for UK Neuro Forum from Neurological Alliance members

The Neurological Alliance (NA) welcomed the UK Neuro Forum initiative and noted enthusiasm about the forum across the NA's membership and people affected by neurological conditions. The NA shared findings from a collective workshop with its member organisations, held to understand what they would like to see from the forum.

The NA's members had raised issues with access to treatments and interventions (depending on where they live, and social and financial situation) and cross-border care, as well as issues in accessing the right care such as specialist and mental health support.

They thought the priorities of the forum should be helping build a workforce that's fit for the future, supporting research, helping build quality data and evidence base, addressing variation in care by identifying minimum standards of care, improving access to support for transition to adult services, and facilitating access to new treatments for those eligible.

The importance of transparency and accessibility of the forum's work was raised, as well as the need to involve people affected by neurological conditions in its work, and to consider effective options to ensure the work of the forum progresses between biannual meetings.

4. Discussion: approach to shared priorities and commonality across all 4 nations

Members discussed shared priorities where it would be considerably more effective to work collectively across all 4 nations and utilise the forum, for example the challenges around cross-border care. The workforce issues, uptake of new medicines and therapies and inadequacy of data were reiterated.

DHSC set out the work of Policy Research Units focusing on dementia, neurodegenerative and neurological conditions. The projects are driven by policy needs and a need to fill an evidence gap around how policies or services can be delivered. While they are England-focused, there is scope for wider work where common issues or challenges which span the 4 nations are identified. The members agreed this is a helpful resource and agreed to work together to articulate core questions and evidence gaps that need to be addressed, particularly regarding workforce and treatments.

5. UK Neuro Forum's input to wider pan-UK workstreams (for example, research and AI)

DHSC expanded further on research, providing a high-level overview of the work of the National Institute for Health and Care Research (NIHR) and a range of strategic groups. The NIHR has a wide range of research programmes where applications for research are accepted. One of the key programmes relevant to the forum is the NIHR Policy Research Programme, which funds the Policy Research Units. Research can also be funded via open competition, which can help build capacity and access to a greater pool of researchers.

DHSC provided an overview of the artificial intelligence (AI) work to date, including the programme where the tool BRAINOMIX, which saves time by helping neurologists to detect issues and interpret scans, had been on trial. Members agreed to further discuss the scope of feeding into future strategic pieces on AI, particularly given the discussions about workforce issues and opportunities for greater AI decision support. Information about the AI Ambassador Network was shared with members.

6. Future agenda items including, for example, WHO's intersectoral global action plan (IGAP) on epilepsy and other neurological disorders

The chair invited members to propose future agenda items, including deep dives on particular issues. The members proposed an item on achieving objectives and targets of IGAP, an item on rare diseases and ensuring people are able to access care and new treatments for rare, complex diseases, an item on superspecialist care services, and a deep dive on workforce.

Regardless of the priorities, it was noted an agreement is needed on a mechanism by which the forum can support change, while collaborating and taking into account limitations, as well as abilities and levers, of different organisations of the forum.