



UK Neuro Forum: terms of reference

Contents

UK Neuro Forum: terms of reference.....	1
Contents	1
Purpose.....	1
Context	2
Timescales and meeting structure	4
Declarations of interest.....	6

Purpose

The purpose of the UK Neuro Forum is to inform policy to help ensure that people with neurological conditions across the UK can access the right services and support.

The forum is advisory rather than a decision-making body, as any recommendations for action in one or more of the 4 countries of the UK will need to be feasible and viable, have ministerial support and, where appropriate, funding secured through a spending review process. In England, due regard will also need to be given to the outcome of the 10 Year Health Plan process.

Key objectives are to:

- bring key stakeholders together and share learning between nations

- discuss relevant service transformation and workforce challenges
- share best practice examples and potential solutions that will add both to the existing programmes of work and wider health and care plans
- explore research needs and potential improvements that would help inform policy

Context

The Neurological Alliance called for a UK-wide neuro taskforce. The petition received over 19,000 signatures under the previous government. In September 2024, DHSC ministers agreed to a biannual neuro forum between the Department of Health and Social Care (DHSC), NHS England, devolved governments and health services and UK Neurological Alliances.

Definitions and scope of the work

Background information

A neurological condition refers to a condition that affects the brain, spinal cord and/or nerves. There are over 600 known neurological conditions, and these can be separated into 4 main categories:

- ‘sudden onset conditions’ such as strokes, traumatic brain or spinal injuries, meningitis, encephalitis and Guillain-Barré syndrome
- ‘intermittent conditions’ such as epilepsy, migraines and the early stages of multiple sclerosis
- ‘progressive conditions’ such as Parkinson’s disease, dementia, motor neurone disease (MND) and the later stages of multiple sclerosis
- ‘stable with changing needs’ such as Tourette’s syndrome, narcolepsy, cerebral palsy in adults and spina bifida

Some neurological conditions are present at birth, while others begin during childhood or as adults. Some conditions can be recovered from completely, but others can cause rapid deterioration or have a slower, more sustained disease progression. Some, like MND, are life-limiting – killing a third of people within a year and more than half within 2 years of diagnosis.

An estimated 16.5 million people in the UK, one in 6 of the population, have a neurological condition; 600,000 people are diagnosed with a neurological condition each year.

Together, neurological conditions cause around 140,000 deaths every year in the UK – one fifth of all deaths – and they are the leading cause of disability

Some conditions are common, such as migraine (which affects 1 in 5 women or 1 in 15 men). Others are rare, such as Guillain-Barre syndrome (which affects about 1,200 people in the UK each year).

Some conditions have a higher prevalence among men, for example Parkinson's disease and epilepsy, and others have [higher prevalence among women](#), for example MS, ME, migraine, Alzheimer's disease and stroke.

In 2019, the estimated cost of neurological disease to the NHS was £4.4 billion. [Neurological conditions cost the UK £96 billion](#).

Scope of the forum

Most neurological conditions will be within the scope of the UK Neuro Forum, except conditions with separate, dedicated workstreams, specifically stroke and dementia. The forum's primary focus will be on areas not sufficiently covered by other policy initiatives. The forum will, where possible, utilise existing frameworks (for example, the Rare Diseases Framework) and governance structures to inform its work.

The forum will seek to work with existing programmes with complementary objectives, where appropriate.

The forum will cover neurology services across the life-course, including adult, and children and young people's services, recognising the prevalence of paediatric neurological conditions and the importance of early intervention in improving patient outcomes in both childhood and adult life.

Current provision

In England:

- approximately 800,000 hospital admissions every year result from neurological problems. Neurological conditions are the third most common reason for emergency hospital admission
- as of July 2024, there are over 1,800 full-time equivalent (FTE) doctors working in the specialty of Neurology in NHS trusts and other core organisations in England. This includes over 900 FTE consultants. As of July 2024, there are over 1,000 FTE doctors working in the specialty of neurosurgery in NHS trusts and other core organisations in England. This includes over 400 FTE consultants. There are 27 specialised neurology centres across England

- the latest data for referral to treatment waiting times in England (September 2024) shows there were over 234,000 patients waiting for a neurology appointment, and 54.0% of patients were seen by a neurologist within 18 weeks

In Northern Ireland:

- care and support is provided to people with neurological conditions in Northern Ireland (NI) from a broad range of services. Some of these are specialist neurology services. Others have a broader community-based focus which are provided by general practice, community based allied health professionals and other community and voluntary based services
- neurology services are provided across each trust area in NI. There is one Regional Neurosciences Centre at the Royal Victoria Hospital in Belfast which provides 18 dedicated neurology inpatient beds for all of NI

In Scotland:

- there are 4 NHS neurosurgical centres in Scotland (Managed Service Network for Neurosurgery)
- outpatient waiting time data in Scotland reveals that the average (median) wait for a first appointment to see a neurologist is 25.2 weeks, [with people in Tayside having to wait 77 weeks](#)

In Wales:

- the Welsh [Government's Quality Statement for Neurological Conditions](#) sets out high level policy aims for what good quality services for neurological conditions should look like across Wales. The quality statement is being implemented through the National Strategic Clinical Network for Neurological Conditions under the governance of the NHS Executive. The aim of the quality statement is to help ensure that people of all ages living with or affected by a neurological condition have timely and equitable access to high-quality services to enable them to live their best lives
- there are an estimated 100,000 people living with a neurological condition in Wales, and [around 2,500 new diagnoses every year](#)

Timescales and meeting structure

The forum meets twice a year (in winter and in summer)

Location

All meetings are either hybrid or virtual:

- DHSC HQ building: Leeds (Quarry House) or London (39 Victoria Street), devolved governments' offices (depending on agreed arrangements for individual meetings of the Forum)
- virtual platform: Microsoft Teams

Working arrangements

The working arrangements of the UK Neuro Forum are as follows:

- DHSC will be responsible for the secretariat, liaison with the members for papers and reporting, planning of agenda items and distributing meeting minutes and actions
- in the case of any conflict, or where the group is unable to reach consensus, the chairs will decide how to resolve the issue
- papers are to be provided to members a minimum of 3 working days prior to each meeting. If it is possible to provide them further in advance than that, the secretariat will
- ground rules and detailed scope for the group will be agreed at the first meeting. This will include a discussion to ensure everyone feels welcome and is able to engage effectively, for example need for breaks during the meeting
- the forum will consider opportunities to make meeting discussions publicly available on a case-by-case basis
- agreement about sharing information outside of the meeting will need to be reached and agreed by the Neuro Forum members. Equally, the production, co-authoring and release of any documents for purposes external to the Neuro Forum requires consensus among the participating members
- members may recommend a guest be invited to the meetings, which would then need agreement from the chair(s) and the secretariat
- the members will review these terms of reference every 2 years, or as otherwise required

Declarations of interest

All members should be aware of the expected standards when it comes to dealing with outside interests, what constitutes a perceived, potential or actual conflict, and what action they must take in those circumstances.

It is the responsibility of individuals to whom this policy applies to declare any relevant interests as soon as they arise and at the start of each meeting once the agenda has been agreed.

Below is a non-exhaustive list of types of interests that it might be necessary to declare:

- financial interests - where a member stands to gain financially, or they can use their status to deliberately prevent someone else from gaining financially
- private shareholdings - where an individual holds shares in a business that the forum has an interest in
- business interests - where an individual holds an interest in any organisation (including directorships) which they could use their official position to further
- insider dealing - insider dealing is a serious criminal offence under the Criminal Justice Act 1993. If in the course of an individual's work they come into possession of information that could be used for financial gain (or other types of gain), this must be treated in the strictest of confidence. It may be necessary to declare any interests that put an individual in a position where they could benefit from holding certain information.
- procurements - where members have direct or indirect financial, economic, or other personal interest which might be perceived to compromise their impartiality and independence in the procurement process