Health and Sport Committee Inquiry
The Preventative Agenda: Neurological Conditions
Neurological Alliance of Scotland submission

Introduction
The Neurological Alliance of Scotland (NAoS) is a forum of not-for-profit organisations and groups representing many thousands of people affected by neurological conditions in Scotland. The Neurological Alliance of Scotland was launched in 2004 to ensure that neurological services are given priority at all levels of health and social care planning.

It now has over 40 member organisations, covering all types of neurological conditions.

NAoS enables third sector neurological organisations and groups to campaign together and speak with an influential voice.

The Alliance has three main aims:

1. **Influencing Policy**
   To inform and influence policy by bringing the needs of people with neurological conditions to the attention of health and social policy makers and strategists.

2. **Raising Awareness**
   To raise awareness and disseminate information about neurological conditions and their impact on individuals and society.

3. **Improvements in care**
   To promote improvements in care for people with neurological conditions

The Neurological Alliance of Scotland’s vision is that ‘*People living with neurological conditions will have access to the best care possible, have control over their lives and be able to live free from ignorance and injustice.*’

**Background to neurological conditions**
There are more than 600 neurological conditions, and they are often complex to diagnose and to manage. People with complex neurological conditions are disproportionately represented amongst those who are the heaviest users of health and social care services.

An estimated one million people in Scotland are living with a neurological condition which has a significant impact upon their lives. Most neurological conditions affect people’s quality
of life and require ongoing treatment and support. Neurological conditions account for one in five emergency hospital admissions and one in eight GP consultations in Scotland.

A quarter of all disabled adults of working age have a neurological condition, and neurological conditions are a major cause of disability and ill health in childhood and older age too. The numbers of people with neurological conditions will grow sharply in the next two decades.

Neurological conditions are caused by damage to the nervous system, often as a result of illness or injury. Some have a genetic basis. For others, the cause of the condition is not known. Many neurological conditions are life-long, and some are also progressive.

The Neurological Alliance of Scotland brings together organisations that support people with all sorts of neurological conditions, spanning childhood to older age.

**Q1: To what extent do you believe the Scottish Government’s approach and the approach by Integration Authorities and NHS Boards towards neurological conditions are preventative?**

It is important to be clear about what is meant by a preventative approach. In the case of neurological conditions overall, it is unhelpful to think in terms of “preventing” conditions. As the Scottish population grows and ages, the numbers of people living with a neurological condition will increase.

The Neurological Alliance of Scotland supports policies to improve Scotland’s population health, although this approach is not effective in terms of reducing the prevalence of most neurological conditions. We know that the prevalence of some neurological conditions, including some types of stroke, migraine and dementia can be significantly reduced by effective public health strategies such as those targeting tobacco and alcohol use, obesity and inactivity.

Treatment of non-neurological health conditions can also make a difference to prevalence. The [Cross Party Group on Heart Disease and Stroke recently reported](#) that improving detection, diagnosis and treatment of atrial fibrillation would reduce the impact of stroke in Scotland.

**Up to 70% of neural tube defects could be prevented if population health strategies increased folic acid levels in women of childbearing age,** and improvements in maternal health could reduce the number of children born with cerebral palsy – but even in cases where some degree of prevention is possible, conditions will not be eradicated.

We also recognise that some individuals may find it easier to manage living with certain neurological conditions if they are fitter than those who are not.
For most of our members, the question is how effectively the Scottish Government, NHS Boards, and Integration Authorities are working to support people with neurological conditions to live as well as possible with their condition. This means enabling people to access the treatment, care and support they need in a timely way that avoids unnecessary deterioration or crisis.

The Neurological Alliance of Scotland was established to address major shortcomings in the provision of statutory services and support for people living with neurological conditions. Historically, NHS and social care service provision has been poor, with unplanned and fragmented services that have not reflected the devastating impact that neurological conditions have on individuals, unpaid carers and families.

There has been some progress, in particular the development of the NHS HIS Clinical Standards for Neurological Health Services. Although the scope of the Standards was limited, these were helpful in raising the profile of neurological conditions within NHS Scotland.

The biggest measurable improvements in services were seen amongst the five conditions which had condition-specific standards – epilepsy, headache, MND, MS and Parkinson’s. There were also generic standards, which were designed to apply to care for all neurological conditions, but the impact of these has been less easy to measure, and many patient organisations did not find them to be particularly helpful in terms of improving support. These standards are now being reviewed by NHS HIS, to broaden their scope and reflect the needs of people with neurological conditions across health and social care settings.

Scottish Government launched the National Advisory Committee on Neurological Conditions (NACNC) in 2016, and is working towards publishing a National Action Plan for neurological conditions later this year. The Neurological Alliance of Scotland has representation on the NACNC. The Action Plan will cover all neurological conditions (as defined by the World Health Organisation). Dementia and stroke are neurological conditions, but have existing national strategies so will not be included, although there may be some overlap with conditions that are covered. Children’s services are not included, although transition from children’s to adult services is specifically covered.

The NACNC’s work to develop an Action Plan has investigated three main areas:

- the lived experience of people with a neurological conditions and unpaid carers/families
- working with ISD to establish the best data on the prevalence of neurological conditions in Scotland
• mapping the existing services that support people with neurological conditions and unpaid carers / families across the NHS, social care including statutory, voluntary sector and private providers

We believe that this approach is needed to start to address some of the issues that exist with support for neurological conditions, including:

• understanding the complexity of the neurological conditions, with essential care and support provided in all care settings and by a wide range of professionals

• the lack of data in all areas that are needed to plan services – including the numbers of people living with neurological conditions and understanding the services and workforce currently available to support them

We would hope that this work would enable Scottish Government, NHS Boards and Integration Authorities to adopt a more preventative approach than they do at present.

The lack of a preventative approach is evident at every stage from diagnosis or identification of a neurological condition. Underinvestment in NHS services is having a significant impact on people with neurological conditions, where diagnosis and ongoing management of long term conditions can be very complex. For example, epilepsy has a misdiagnosis rate of 20-30%, and many people do not have their epilepsy optimally controlled. This means that some people are experiencing seizures that could be controlled, resulting in unnecessary costs ranging from emergency services, hospital admissions and ongoing social care and support needs as well as severe impacts on quality of life for people with the condition. In epilepsy and a number of other conditions, a shortage of consultants and specialist nurses has a direct impact on individual outcomes.

Even once diagnosis is established, people with many long term conditions lack any support from specialist teams, and have to find a referral route back in when issues arise rather than working with them to prevent issues arising or to anticipate and adjust to declining function. Because many neurological conditions have a very wide range of symptoms, people often require input from a range of health professionals, and specialist nurses and multi-disciplinary teams can provide excellent care and support. But these are often difficult to access. There is a shortage of allied health professionals who have training and knowledge in working with people with neurological conditions, which is essential to provide appropriate care.

For people with complex support needs but whose condition does not require ongoing medical and nursing input, it can be very challenging to access community-based support which enables them to maximise their function and participation in their community. In our experience, it is very difficult to engage with integration authorities about the support they provide to people with neurological conditions. The perception is that integrated services
provide generic care, so they do not identify the needs of the people they support with neurological conditions, and do not readily engage with services that are seen to be condition-driven. This means that many people with neurological conditions are missing out on the support they need.

For example, Bobath Scotland undertook some work with health and social care partnerships (HSCPs) to improve the community-based support available for people with cerebral palsy and found that:

- establishing who was receiving services was challenging
- building relationships with HSCP staff is important and can result in improved support – but it takes a huge amount of time
- some HSCPs have completely refused to engage

Funding issues are also hitting local community based support services very hard, and as eligibility criteria for social care support are tightened, people are not getting access to preventative care.

We would also identify a lack of information and support for people with neurological conditions after they are diagnosed. Many people simply do not receive the information that they need to identify and anticipate issues in their care, which prevents people from protecting their own health and knowing when more input is needed.

There is also a lack of support for unpaid carers and families, who often take on a very high caring workload because the person they support has complex needs. A recent study of carers for people with advanced Parkinson’s in North East England found that they were typically providing care for 16 hours day, and that the majority of them received no formal social care support. The Neurological Alliance hopes that the Carers (Scotland) Act will help to identify carers’ needs more systematically, and provide more access to support.

**Q2: Is the approach adequate or is more action needed?**

More action is definitely needed, and we hope that the Neurological Action Plan will help to deliver some of the improvements required. Neurological conditions remain a Cinderella area, despite the huge impact on individuals and families. Previous work has not addressed the full range of experiences of people with neurological conditions in Scotland.

The Action Plan needs to reflect the range of settings that people receive care - not just in acute hospital wards and outpatient clinics, but also in primary, community and social care settings. For most people living with neurological conditions, the services that they use most will be provided as part of integrated health and social care arrangements, although they may also require some specialist neurological input, and in some cases their care will be led by neurological teams. Many conditions also require treatments which involve medical
specialisms other than neurology - for example older people’s medicine, genetic medicine, psychiatry, gastro-enterology, respiratory medicine.

It is important to highlight some of the third sector-led work which is also working to improve the support and care that people with neurological conditions receive. For example, the National Care Framework for Huntington’s seeks to ensure that the care and support provided to individuals and their families living with Huntington’s disease takes account of their specific health & social care needs throughout their experience and is currently being rolled out across Scotland. The UK Parkinson’s Excellence Network brings together health and care professionals to share skills, tools and insights and improve the quality of care. It also coordinates a UK wide audit to evaluate the care people receive. There are three multi-disciplinary regional groups in Scotland, covering the West, East and North of the country. The Scottish MND Register provides accurate statistics about who gets MND in Scotland, where they live, what age they are and what gender they are. It helps to build a broad picture of why some people get MND, and can be used to audit care standards across different health boards and local authorities, and the.

**Q3: Are the services for neurological conditions being measured and evaluated in terms of cost and benefit?**

There is currently no active measurement of services for most neurological conditions, although some conditions have better information than others through mechanisms including audits and registers. We believe that evaluation and monitoring must include patient and carer reported outcome and experience measures.

The NHS HIS Clinical Standards are currently under review, but we are concerned that no resource has been identified to monitor the impact of these standards once they are developed.