Thank you for the opportunity to provide a written submission to the committee, and please again accept my apologies for being unable to attend the session.

I am the current Chair of the National Advisory Committee for Neurological Conditions (NACNC) and also Specialty Advisor for Neurology to the Chief Medical Officer. In my day job I am a Consultant Neurologist in NHS Lothian.

The Scottish Government’s NACNC advises on the development of national policy on neurological conditions. Scottish Government has stand-alone policy structures for Stroke and Dementia, thus whilst these are undoubtedly neurological conditions, they are not being considered by the NACNC as part of its work. Similarly, it should be noted that Stroke and Dementia services are organised and delivered separately in NHS Boards.

**Neurological conditions**

Neurological conditions are those arising from diseases and disorders affecting the brain, spinal column or nerves. They include primary headache syndromes (such as migraine), epilepsy, cerebrovascular disease including stroke, inflammatory disease (such as multiple sclerosis), neurodegenerative disorders (such as motor neurone disease, Parkinson’s Disease and dementia), Infections (such as meningitis and encephalitis) cerebral palsy, genetic conditions (such as Huntington’s Disease and ataxias), traumatic brain injury and functional neurological disorders.

Neurological conditions vary in their severity and impact on individuals. Some neurological conditions are common (migraine, functional neurological disorders) and others very rare. (e.g. Creutzfeldt-Jakob Disease)

**Impact on health and life expectancy**

“The most recent estimates show that stroke is the second highest cause of morbidity and mortality worldwide. Dementia, meningitis and migraine rank in the top 30 factors in disability-adjusted life years, and epilepsy in the top 50, out of 315 diseases and injuries included.”

*World Health Organisation, ATLAS Country Resources for Neurological Disorders, 2017*

In Scotland the Global Burden of Disease Study looked at the extent to which different diseases affect Scotland’s Health and Life Expectancy. This study used DALYS (Disability Adjusted Life Years) as a measure, whereby one DALY can be
thought of as representing one year of healthy life lost. The sum of these DALYs across the population (burden of disease) is a measure of the gap between current health status and the ideal health situation where the population lives to an advanced age, free of disease and disability.

Data from 2015 illustrate the impact of neurological conditions in DALYs:

- All neurological disorders: 138,600
  - Alzheimers and Other Dementias: 56,300
  - Stroke: 56,900
  - Migraine: 17,800
  - Epilepsy: 13,400
- Cardiovascular diseases: 213,100
- Chronic respiratory diseases: 81,800

NACNC recognises that neurological conditions often lead to serious physical, cognitive and psychosocial limitations, for individuals and their families affected by these conditions.

**National Advisory Committee for Neurological Conditions**

The NACNC was established in July 2016 to drive improvements in the care, treatment and support for people living with neurological conditions across Scotland by:

- Providing advice to Ministers and Scottish Government Health and Social Care Directorates on neurological conditions to support the development of national policy(ies);
- Being widely recognised as having the ability to lead, collate and reflect the views of the neurological community, including health care professionals, third sector organisations and service users;
- Creating and offer opportunities for networking and communication for all neurological stakeholders;
- Improving outcomes for people with neurological conditions by working to embed improvement across relevant services in line with the Quality Strategy aims to support and ensure safe, effective and person centred care.

The NACNC includes clinicians, patients and carers, as well as representatives from the third sector, professional groups, NHS Boards, Integration Joint Boards and research/academic fields, and the Health and Social Care Alliance. It seeks to harness and reflect expert advice and support across the neurological community.

The NACNC also has two deputy chairs who bring balance to the leadership team, Susan Walker and Stephanie Fraser, providing experience from NHS service management and the third sector respectively. The NACNC is supported by Scottish Government officials from the Strategic Planning and Clinical Priorities Team.
National strategies

A survey by the World Health Organisation found that 24% of countries report stand-alone neurological health policies. (These included policies on dementia or stroke).

Stroke has been a clinical priority for NHS Scotland for over 15 years. Over this time there have been significant improvements in treatment and stroke services across the country. A national Stroke Improvement Plan was published in 2014.

Scotland's National Dementia Strategy 2017-2020 builds on progress over the last decade in transforming services and improving outcomes for people affected by dementia.

There is currently no national strategy or policy in Scotland for other neurological conditions. However, on 14th September 2017, the First Minister announced in the Scottish Parliament that the NACNC had started work to develop Scotland’s first National Action Plan on Neurological Conditions.

National Action Plan on Neurological Conditions (NAP)

The NACNC is supporting the development of the NAP. A project team has been established to take this work forward, which sits as a sub-group of the NACNC and meets monthly. The project includes 5 separate activities that will inform the development of the NAP.

1. Lived Experience
   This is a qualitative approach to understanding people’s experiences of care, and their priorities for change. Scottish Government commissioned this from the Health and Social Care Alliance, in partnership with the Neurological Alliance of Scotland. The Lived Experience Survey is currently open to people living with Neurological Conditions.

2. Neurological Disorders Analytical Project
   National Services Division’s Information Services Division is gathering data on prevalence of neurological conditions and NHS activity. The first phase of ISD data was presented to NACNC in February 2018. Ascertaining prevalence is proving challenging, and ISD are currently advising the NACNC and Scottish Government on how best to take this forward.

3. Policy Engagement
   This is being addressed within Scottish Government by the Strategic Planning and Clinical Priorities Team and with colleagues from HealthCare Improvement Scotland. This is to ensure the NAP is coherent with the new neurological standards as they are developed and the wider policy context.

4. Mapping of Neurological Services
   A Survey of Service Providers led by the NACNC Executive Team. This aims to map neurological services across the country. There has been a low response rate from Integrated Joint Boards perhaps reflecting that services in their Health...
and Social Care Partnerships are organised on a broader population basis (such as frailty or physical disability) rather than for specific conditions.

5. Neurorehabilitation/HSCP Engagement
   This will be developed by the project team, on completion of the above tasks.

Development of the NAP will be achieved with opportunities for extensive engagement and consultation from clinicians, NHS service managers, AHPs, IJBs, Third Sector organisations and patient representatives.

**Timescale**

It is the intention that Scottish Government will publish the draft NAP in Autumn for formal consultation, and to publish the final plan by the end of 2018.

I hope this information is helpful to the committee.

Dr Richard Davenport
Chair, National Advisory Committee for Neurological Conditions

17 March 2018