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12 February 2025

Re: Concerns over the loss of a neurology framework for Scotland

## **Dear Cabinet Secretary**

I am writing as the Programme Director of the <u>Neurological Alliance of Scotland</u>, a diverse coalition of 55 charities of all sizes that support an estimated one million children, adults and older people with neurological conditions and those who are closest to them. Over the past five years, our alliance has been an integral vehicle for the delivery of the Neurological Care and Support Framework for Action (2020 - 2025). We have worked closely with Scottish Government colleagues to support the Framework and continue to do so, through the newly established cross sectoral neurology network.

Whilst the Framework has provided exceptional focus on neurology and neurological services in Scotland, we do not believe that all the priorities from the framework will have been delivered, particularly as the committed £4.5m spend on the framework has not materialized in full. The challenge of the Covid-19 pandemic is fully acknowledged, and yet it cannot be used as a reason for not fulfilling the intentions of the framework, particularly given this underspend.

Across the neurological third sector, there is a growing sense of anxiety that at the end of the Framework in 2025, other than a Government review of the framework, there will be no attention, ongoing strategy or framework to manage the growing burden of neurological conditions. The need for an ongoing strategy and focus on neurological services continues to be identified by the National Advisory Committee on Neurological Conditions and by NAoS members.

As you will be well aware, neurological conditions are one of the most frequent and disabling of all non-communicable diseases in the UK, estimated to cost £96bn to the UK economy. We also know from the Scottish Burden of Disease (November 2022) report, that prevalence of neurological conditions in Scotland, is going to increase: "Absolute increases in annual disease burdens are forecast to be largest for cardiovascular diseases, cancers, and neurological diseases." Public Health Scotland also acknowledge that whilst the Scottish population is going to fall, there will be as much as 21% increase in people affected by disease by 2043, with a slightly bigger impact on men.

We attended the Long-Term Conditions strategy meeting on the 20<sup>th</sup> November 2024 along with other long term condition charities. We fully understand the logic in creating an overarching strategy for long term conditions. Many people live with co-morbid conditions - we know that 86% of people living with a neurological condition are impacted by poor mental health and suicide is a particular risk factor for conditions such as epilepsy. But, for those with comorbidities, disability is most likely to be caused by their main condition, which for 1 in 6 people, or 1,000,000 people in Scotland, will be as a result of their neurological condition.

The fact remains that neurology has been highlighted as one of three disease burden areas most likely to have a population impact, both now in 2025 and by 2043 and is the leading cause of ill health globally, surpassing cancer and cardiovascular disease. It is Scottish Government's responsibility to plan healthcare for the population.

Given there is a forecast 36% increase in disability adjusted life years for males and a 34% increase for females aged 65-84 by 2043, and knowing that statistically the cause of these disabilities is likely to be due to poor heart health, cancer or neurological conditions, we cannot understand why Scottish Government risks failing to give these three conditions the due care and attention they deserve by not immediately prioritising these three disease areas with specific strategies in addition to an overarching long-term conditions strategy.

As discussed directly with officials, the draft Population Health Strategy also needs to include older people. Slides from the meeting held on 1<sup>st</sup> October 2024 indicated that this strategy was only going to consider health from birth to the end of working age. This is a major flaw, given the majority of incidence of neurodegenerative diseases including MND, Parkinson's and dementia impact people over the age of 65. It is crucial that there is clarity over the support being planned for people of all ages. We also urge the Population Health Strategy to build on the work of the Neurological Framework. It was concerning at this meeting to note that officials seemed unaware of the work undertaken on prevalence of neurological conditions for example. We are therefore fearful that, yet again, the needs of people with neurological conditions are being marginalized.

We are committed to supporting Scottish Government in creating a new neurology strategy that continues to build better pathways across more conditions, to build the workforce, to share knowledge and to drive better services and outcomes for people. These improvements cannot be driven by the new voluntary led neurology network alone. It has never been more important to invest in support for people impacted by neurological conditions.

We have made considerable progress with the implementation of the Framework, which is in danger of being wasted and lost if a commitment to a new plan for this significant sector cannot be agreed.

<sup>&</sup>lt;sup>1</sup> The value of action: mitigating the impact of neurological disorders in the United Kingdom - Economist Impact

<sup>&</sup>lt;sup>2</sup> Scottish Burden of Disease Forecasting Briefing

Together we can certainly make a difference and the neurological third sector stands ready to contribute to a new neurology strategy.

We request an urgent meeting with you and your officials to take this forward. We look forward to receiving dates that are suitable for you and we will make arrangements at our end to fit in with them.

Kind regards,

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## **Alice Struthers**

**Programme Director of the Neurological Alliance of Scotland** 

CC: Minister for Public Health and Women's Health, Jenni Minto MSP



































































