24 April 2018

Dear Cabinet Secretary

Preventative Agenda: Neurological Conditions

The Health and Sport Committee as part of their Preventative Agenda inquiry agreed to undertake a series of short focussed pieces of work looking at specific areas of public health activity with a view to assessing how far each activity is addressing the preventative agenda. The Committee have agreed to produce a report in the autumn once all these pieces of work have concluded, with individual findings and suggestions being reported by letter to the Scottish Government as appropriate.

The latest topic considered was Neurological conditions and having considered the evidence received the Committee agreed I should write to you setting out their thoughts.

Background
The Committee heard evidence on 27 March from a panel of witnesses which was supported by a number of written submissions.

A neurological condition is one that affects a person’s brain or nervous system. They can be genetic, such as Huntington’s; progressive, such as Parkinson’s disease, dementia and Multiple Sclerosis; present from birth, such as cerebral palsy. Some can be caused by brain injury – impact, stroke or illness – for example certain tumours. Most are life-changing and affect
someone’s ability to live independently and can affect their mental as well as their physical health.\textsuperscript{1}

It is estimated that one million people in Scotland are currently living with a Neurological condition.\textsuperscript{2}

\textbf{Activity from 2006}
Following a Scotland wide review in 2006 looking at the provision of services for people with neurological conditions clinical standards were developed in 2009. These were designed to address existing variations in provision of services and result in an improvement in care for sufferers. A report into progress in 2012 found some progress but concluded there was much more to do to meet the 2009 standards.

In 2013 the National Neurological Advisory Group (NNAG) was set up to oversee standards and provide support to health boards in implementing improvements. A self-assessment by boards the following year disclosed 40\% of the essential criteria within the standards were being met.

In 2015 NNAG was put under review and no subsequent assessment has been undertaken. Although at the end of the year following FOI requests Sue Ryder reported no health board was meeting all the standards. In 2017 only 4 health boards had the required three year neurological service delivery plan, all were due to expire that year. After publication of the Sue Ryder report the Scottish Government acknowledged HIS were responsible for setting and reviewing standards for clinical governance and assessing performance against the standards. HIS had not undertaken any work on the 2012 neurological standards. \textbf{The Committee would be interested to understand what mechanisms are in place to monitor the priority setting and ongoing functions of HIS by the Scottish Government.}

In February 2016 the NNAG was “refreshed and streamlined” with an initial 2 year programme and a remit to reflect the ambition to drive improvements in the care, treatment and support available for people living with neurological conditions across Scotland. Later in 2016 The Scottish Government’s National Advisory Committee on Neurological Conditions (NACNC), was formed, taking over the role of NNAG. They began work with Information Services Division (ISD) Scotland to develop the means to collect data that will reliably indicate prevalence of neurological conditions, where people with neurological conditions live, including care homes, waiting times, and delayed discharge from hospital. Unfortunately the NACNC, who have not met this year, declined an invitation to provide evidence to the Committee.

\textsuperscript{1} SPICe Briefing
\textsuperscript{2} NPC \url{http://www.thinknpc.org/publications/neurological-conditions-in-scotland-a-guide-for-funders/}
National Action Plan and Revised Standards
The Committee understand NACNC will publish a draft National Action Plan by summer 2018 and revised standards are due from HIS early in 2019. The revised standards are anticipated to cover health and social care. The Committee considered the HIS scoping report for new standards and were surprised not to learn from it the underlying purpose and objective of the exercise. Without a clear understanding of what and how any new system is to be used there is a concern the standards will do no more than the previous set and make only a statement of expected levels. The Committee would welcome clarity as to the intended purpose of this work and how the standards will be implemented, monitored and enforced.

The Committee would be grateful for confirmation and greater specification in relation to the above timings, namely when the action plan will be published, when revised standards will be available and when the data being collected will be available for use.

The Committee would also appreciate detail on how compliance with the standards will be monitored both centrally and in each board and who will be responsible for this in each area. The Committee would support an accountable officer being nominated in each health board with responsibility for ensuring compliance and public reporting of performance on at least an annual basis.

Data Collection
In relation to data collection, different viewpoints were expressed as to how that could be achieved with a particular emphasis on minimising data entry. The Committee heard that sufferers of neurological conditions are “immersed and interspersed” in every part of health and social care services, so one of the key requirements is to ensure that new data collection is streamlined, not burdensome and captures the experience and full needs of those with neurological conditions.

The Committee would welcome your views on the extent to which existing systems are capable of producing adequate data, failing which, detail of any proposals and timescales to redesign systems to automate collection.

Delays in Treatment
The Committee heard current delays were caused by a combination of lack of funding and staff shortages. On funding it was suggested this area was not a priority for health boards. The Committee would welcome the Scottish Government’s views on this.

Role of Integrated Joint Boards
While responsibility for neurological conditions is not a specific delegated function for IAs, most of the services IJBs are responsible for organising are the ones of most relevance to people living with neurological conditions, adult social and community health services and key hospital-based services.
Given the amount of work required to support people to live day to day with neurological conditions the Committee were surprised to learn of a piecemeal approach to the responsibility for the delivery of services across the country. They heard of confusion between health boards and local authorities as to who was responsible for the provision of rehabilitation services and significant differences in the provision of service plans for sufferers. **The Committee would welcome the thoughts of the Scottish Government in relation to the provision of neurological services by IJB’s.**

**Short-term Funding**

The Committee again heard about short-term, non-recurring funding and how at the end of the pilot period, seemingly regardless of the outcome achieved, the service being funded disappears. This has been an issue across a number of inquiries; **will the Scottish Government update the Committee on what steps have been taken to mainstream successful pilot projects?**

**Staff Shortages**

A shortage of both medical and nursing staff was noted by all witnesses. We heard about the role of specialist nurses and the benefits they bring, not just to patients but also savings on medical time. Equally the benefits from having access to other healthcare professionals such as physiotherapy and occupational therapy were stressed. **The Committee would welcome an update on how shortages in each of these areas are to be addressed.**

It was suggested to us that clinical delays were exacerbated by the use of locum consultant neurologists (in Forth Valley) brought in as a result of a desire to meet waiting time targets.³ If as suggested one locum session led to “chaos” with high levels of return appointments and numbers of complaints we wonder about either the competence of the locum described or the level of training and support in local services that was provided. The Committee find it difficult to accept it would have been quicker for the witness to see 100 patients than “clear up the mess afterwards” from a single locum clinic. **The Committee would welcome the views of the Scottish Government on the various aspects arising from the above scenario.**

**Specialist provision shortages**

The Committee heard about a shortage of specialist nursing and other healthcare provision for sufferers from neurological conditions to receive care in the community. In particular they understand 86% of people with neurological conditions are in residential care homes for the elderly, including around 250 young adults. We heard about people being in the wrong care setting, usually in an acute hospital because services are not available down the line. **The Committee would be interested to know what plans the Scottish Government has to create increased accommodation for sufferers including specialist accommodation for young sufferers. The Committee would also be interested in understanding how many people with neurological conditions are currently included within the delayed discharge numbers in acute settings.**

³ Official Report 27 March 2018 column 28
Cost Benefits
Turning now to the costs, and in particular the increased costs, arising from treating sufferers in the wrong or inappropriate care setting. The Committee heard various estimates of costs of care. Previous work undertaken for Quarriers identified significant reductions in hospital admissions and associated costs for epilepsy sufferers when specialist treatment was provided in Quarriers. Sue Ryder provided evidence around an economic model of neurological care undertaken with support from the New Economics Foundation which suggests, on a small scale study, savings ranging from 45% to 75% to the health economy.

The Committee would welcome detail on ways in which the Scottish Government intends to increase the use of cost benefit analysis across the wider health service.

Set against the above the Committee also heard that “savings” made by structural changes in specialities do not accrue to the speciality but for example produce notional “savings” in emergency departments. This, it was in effect suggested, produces a disincentive for specialities to invest in activity and changes which could produce savings as they do not get the opportunity to re-invest the sums saved. While the Committee understands the point being made this is a prime example of silo mentality with departments concerned solely with their own budgets to the detriment of the wider health service and quite possibly their patients. The Committee would be interested on how the Scottish Government can incentivise clinicians and others to accrue some benefit from the identification of savings as described.

Caring for Carers
The final area upon which evidence was heard centred around support for carers for those affected by neurological conditions. The Committee would welcome from the Scottish Government details of who will be responsible for bringing forward suggestions to cover the delivery and monitoring of services to carers within the proposed strategy and standards.

The Committee would be grateful to receive your response to this letter by Friday 18 May.

Yours sincerely

Lewis Macdonald
Convener
Health and Sport Committee