22 May 2018

Dear Lewis,

Thank you for your letter of 24 April 2018 regarding Neurological Conditions in relation to the Committee’s investigations into the Preventative Agenda.

The Scottish Government is committed to improving services, treatment and outcomes for everyone in Scotland living with a neurological condition. That is why we are currently working with partners to develop Scotland’s first National Action Plan on Neurological Conditions (NAP).

On the advice of our National Advisory Committee for Neurological Conditions, throughout this letter I will refer to ‘people living with neurological conditions’ rather than ‘sufferers’.

Evidence session

Arrangements for giving evidence to the Committee have not been ideal. Unfortunately, the Committee initially invited people who were members of the previous National Neurological Advisory Group (NNAG) to give evidence – the NNAG was disbanded in 2015. Invitations were not extended to the Chair and co-chairs of the National Advisory Committee for Neurological Conditions at that point.

As a result of the delay in extending the invitation, the Chair of the National Advisory Committee for Neurological Conditions, Dr Richard Davenport, was unable to comply with his employer’s (NHS Lothian) requirement to give 6 weeks’ notice, which would have allowed clinical commitments with patients to be rescheduled. The Deputy Chairs also had prior commitments, which included annual leave. It is therefore unfortunate, given the short notice, that they have been recorded as 'declining to give evidence', particularly as Dr Davenport had provided a written submission to the Committee in advance of the session.

The Committee may wish to note that Dr Davenport and the Deputy Chairs, Mrs Susan Walker (NHS Greater Glasgow and Clyde) and Mrs Stephanie Fraser (Bobath Scotland), have provided valuable support and advice to the Scottish Government via their work on the National Advisory Committee for Neurological Conditions over the past two years.
National Advisory Committee for Neurological Conditions (NACNC)

In 2015 a review of the NNAG was carried out and it was disbanded. The NACNC was established in its place and held its first meeting on 11th July 2016.

NACNCs’ objectives include improving outcomes for those with neurological conditions by working to embed improvement in NHS Boards, Integrated Joint Boards and Local Authorities for safe and effective treatment and care. The NACNC does not currently have a role in monitoring standards within services. The NACNC membership is comprised from all sectors across the neurological community, including clinicians, people living with neurological conditions, the third sector, NHS Boards and Integrated Joint Boards.

Members of the NACNC met in February 2018 to hear a presentation from NHS Information Services Divisions (ISD) on the prevalence of neurological conditions; to review data sets provided, and to discuss the next phase of work with ISD. This work is informing the development of the NAP, reflecting our experience of supporting the infrastructure for quality improvement work more generally – using data to support the identification of areas for local improvement aims (as opposed to national monitoring of compliance with standards).

The full NACNC met earlier this month and the project group which is leading on the NAP meets monthly. More details on the NAP/NACNC are provided in the response to the Committee from Dr Davenport dated 17 March 2018, which is attached as an annex to this letter.

National Action Plan and Revised Standards

When the NAP project has concluded the Scottish Government will publish a draft National Action Plan on Neurological Conditions. There will be a public consultation on the Plan, which we hope will take place in the Autumn of 2018. Healthcare Improvement Scotland (HIS) are planning to publish the revised standards in 2019.

I should stress that the Scottish Government and the NACNC have no formal role in the development of the revised standards. That process is wholly independent and owned by HIS. However, in order to ensure that the new standards coincide and take account of the NAP, HIS and Scottish Government are in regular contact over these pieces of work.

The Health and Social Care Standards, developed by HIS, set out the standards people should expect when using health or social care services. These standards are being implemented from 1 April 2018 and also cover many of the issues which people accessing neurological healthcare services have identified as being important to them.

Healthcare Improvement Scotland

Q: The Committee would be interested to understand the mechanisms in place to monitor the priority setting and on-going functions of HIS by the Scottish Government.

Q: The Committee would welcome clarity as to the intended purpose of this work and how the standards will be implemented, monitored and enforced.

Q: 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.

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It may be helpful if I explain that Healthcare Improvement Scotland is a public body established by the Public Bodies Act 2010. It supports quality improvement across health and care through four pillars of activity – quality improvement support, evidence including standards, scrutiny and assurance and participation. Its funding and strategic priorities are agreed with the Scottish Government annually, and performance is reviewed through monthly and quarterly meetings with officials. A formal annual review takes place each year to assess performance against its financial and work plans. The review includes opportunities for staff and the public to raise questions.

The role of standards are to provide a statement(s) of an expected level of service which demonstrates delivery of person-centred, safe and effective healthcare. The standards should also promote understanding, comparison and improvement of care, and support national consistency and/or local improvement.

It is the responsibility of the organisation that provides care and support for the person living with the relevant condition to ensure the implementation of HIS standards. Through the ongoing development of HIS Quality of Care Approach the Scottish Government will support organisations to conduct regular, open and honest self-evaluation using the Quality Framework and associated organisational self-evaluation tool.

Boards are responsible for the provision of care and for meeting standards and demonstrating this is part of their local clinical governance structures.


On the Committee’s proposal to have a nominated officer in each board responsible for ensuring compliance with standards, this would not align with wider policies and governance arrangements in place for supporting local change and improvement within systems. Work to support change and improvement in quality is not condition specific. This reflects evidence that people do not want to be primarily considered or defined by their healthcare condition. People with neurological conditions want to be part of a care delivery system that considers what matters to them and provides safe, person-centred and effective care.

This is more likely to be provided consistently if local leadership and staff develop appropriate systems across all of the various processes impinging upon neurological services and not simply for individual diagnoses.

Data Collection

Q: 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.

It is not currently possible to provide an accurate answer to this question as delayed discharge data is gathered by the name of the specialty that the person is in at the date of discharge. Many health boards do not beds listed as neurology specialty beds, some may be listed as medical, care of the elderly or rehabilitation specialties. So people with a neurological condition may be in another specialty and so not show as a neurology delayed discharge, although they will be in the overall numbers.
On behalf of the NACNC, ISD were recently commissioned by the Scottish Government, to provide summary data for a landscape analysis of an extensive list of neurological conditions.

This data included inpatient and outpatient hospital activity, hospital waiting times, mortality data and prevalence data (for a limited number of neurological conditions). This work involved pooling across national health data collections already collected by ISD. These sources can provide useful information on the extent and impact of neurological conditions. This data will be used to inform the recommendations of the NAP.

The committee may be interested to note that ISD currently has an on-going Health and Social Care Data Integration and Intelligence Project. ISD has been working with the Scottish Government on an important initiative to merge the Scottish Government Social Care Survey and the ISD Source Social Care data. Social care data will now be collected nationally in a single solution via a revised Source Social Care dataset which will meet the combined purposes of the two previous arrangements.

Under this new streamlined approach ISD will assume responsibility for the publishing of official statistics on social care, previously the remit of the Scottish Government. The original main purpose of the Source Social Care data, to support Partnerships’ information and intelligence requirements, will be advanced considerably on the strength of the new arrangements.

The ISD/Scottish Government team have held a series of consultation events with Partnerships/Councils. Feedback from these events has been used to assist any final decisions regarding the new data collection, definitions guidelines, file specification and frequency of submissions. All of these are available on the health and social care integration dataset page.

**Delays in treatment**

Q: 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.

The Scottish Government is committed to improving services, treatments and outcomes for those living with neurological conditions. We will continue to work with HIS and Boards to ensure the new standards drive real improvements in neurological healthcare services.

We are delivering record health spending in 2018/19, increasing health funding by £400 million, with frontline NHS Boards receiving an additional 3.7% increase which includes £175 million to help deliver service improvements and reform in our NHS.

We are working with Boards to ensure that all reasonable steps are taken to make best use of these available resources. Our overriding priority is to ensure patients continue to receive first-class care

In November 2017 I launched the new Access Collaborative Programme which looks to improve the way elective care services are managed across Scotland and reduce waiting times for patients. The collaborative is supported by £4 million of funding. The Scottish Collaborative have developed a number of fundamental principles that will shape and prioritise the way in which services are provided in the future. They will consider neurology services as part of their remit in 2018.
In regards to the way in which boards prioritise their spending it may help if I explain that the role of the Scottish Government is to provide policies, frameworks and resources to NHS Boards so they can then deliver services that meet the needs of their local populations.

The provision of healthcare services is the responsibility of local Boards, taking into account national guidance, local service needs and priorities for investment. It is the responsibility of each board to then decide where funding should be invested within their area, based on local service needs and priorities for investment.

**Role of Integrated Joint Boards**

*Q: The Committee would welcome the thoughts of the Scottish Government in relation to the provision of neurological services by IJB’s.*

The Public Bodies Joint Working (Scotland) Act 2014 sets out the responsibilities of Integration Authorities and the principles which underpin integrated health and social care. The principles focus around the need for services to be provided in such a way as to improve the wellbeing of service users by ensuring resources are used effectively and efficiently to deliver services. The Scottish Government’s expectations for these principles are set out in statutory guidance (http://www.gov.scot/Resource/0046/00466005.pdf).

The responsibilities of Integration Authorities are set out in the Integration Scheme for each area. Each Integration Authority must produce a strategic commissioning plan and the Scottish Government would expect to see these principles applied in such plans.

The Integration Joint Board (IJB) should then commission services from the Health Board and Local Authority through the use of directions in line with the strategic commissioning plan and allocate resources accordingly. The Local Authority and Health Board must comply with these directions.

Strategic Commissioning by Integration Authorities is not just about producing a plan. It is about planning and making decisions about how best to meet the needs of their local population, including taking account of specific care groups and people with particular conditions, using the combined resources available. This requires close working with professionals and local communities to deliver sustainable new models of care and support that are focused on improving outcomes for people.

Scottish Government officials met recently to discuss how we can better address these challenges across the piece and are looking at how to take this forward in partnership with Chief Officers. This initial meeting included colleagues from learning disability, autism, dementia and neurological conditions policy teams. This should be seen within the wider context of Integration Authorities having to plan and design services across their population, utilising the integrated budget available to them, prioritising as appropriate, based on local needs.

**Short-term funding**

*Q: 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?*

Scottish Government regularly supports third sector organisations who are looking to offer innovative solutions in health and social care, and will offer funding to enable small scale tests.
We work closely with our stakeholders over wider implementation, offering support and advice on how best to share the local learning and roll out projects more widely across the country, taking account of specific local issues. Not every project will deliver improved outcomes, which is why such approaches are tested.

An example of such a project is the National Care Framework for Huntington’s Disease. We have been very proud to support Scottish Huntington’s Association (SHA) develop the Framework over the past 3 years. We have so far provided £180,000 (£60,000 per year) and are currently in discussions with the organisation over future support.

This work is being closely monitored across the world. Last year SHA presented the framework at a Huntington’s Disease conference in Oslo. Since then a delegation from the Norwegian Government and its key stakeholders, as well as a delegation from the Vanderbilt Neurosciences Clinic in Tennessee, have visited Scotland to learn more with a view to replicating the framework in Norway and the USA. SHA will also be presenting the framework to the European HD Network (EHDN) conference in Vienna later this year.

We are continuing to work closely with SHA on the development of the framework. We believe this work has real potential to transform care for people living with Huntington’s Disease. The approach also offers the potential opportunity to develop such a framework across neurological conditions and we are currently discussing this with the Neurological Alliance of Scotland.

**Staff Shortages**

Q: 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.

In terms of recruitment the Scottish Government recognises the crucial role and benefits that both medical and nursing staff play in providing care for people with neurological conditions.

Since 2006 the number of Neurology consultants has increased by 75% with the vacancy rate currently sitting at 9.7%. In 2017 100% of training posts in neurology were filled. I am also pleased to advise that a new recruitment campaign for 2018 is currently underway to attract more people in to the nursing profession.

Furthermore the Scottish Government is investing an extra £2.5 million of recurring funding into specialist nursing and care fund to boost numbers of, and access to, specialist nursing. NHS staffing as a whole by more than 10% since September 2006 to a record high, including a 47.1% increase in medical and Dental Consultants.

Scotland is also the first nation in the UK to publish a National Health and Social Care Workforce Plan. Published in 3 parts, the Plan brings together NHS, Social Care and Primary Care staffing to develop the multi-disciplinary workforce necessary to continue to deliver the high standard of care we have come to expect.

Part 1 of the plan focusses on the acute NHS, while Part 2 covers workforce planning in social care. Part 3 sets out our strategy to recruit new and retain existing GPs, along with our plans for the wider primary care workforce.
Taken together, the Plan and its annual integrated updates from 2018 onwards will strengthen and harmonise workforce planning practice, take full account of the future demand for safe and high quality services for Scotland’s people and work to accurately identify gaps in supply. Future benefits and improvements will impact on all service users and staff across Scotland.

Specialist provisions shortages

Q: 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 Scottish Government believes that care should be delivered as close to home as possible and that people should be empowered to live independently in their communities, through supported living arrangements.

This is why we have integrated health and social care, bringing together approximately £8.5 billion of resource previously managed separately by NHS boards and local government to ensure care is well-joined up and agencies work together to support people in their communities.

Carers

Q: 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.

As part of our work on the NAP, officials are engaging across Scottish Government to consider how the plan fits with other initiatives which are being progressed/implemented under the Programme for Government.

Discussion around the wider work we are taking forward on support for carers is part of that engagement.

I trust that this letter will be helpful to the Committee.

Best wishes,

SHONA ROBISON
LETTER FROM DR RICHARD DAVENPORT TO HEALTH AND SPORT COMMITTEE

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

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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

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