I am delighted to provide a response to your targeted call for views. I have been asked to do so on the basis of my previous involvement as lead of the Data and Audit Group of the National Neurology Advisory Group. However, I relinquished that role over a year ago, and what follows should be taken in that context. I have also found it difficult to separate out the extent to which the views below were shaped by my experience in that role, rather than from 13 years as a Consultant Neurologist; 10 years as Clinical Lead for Neurology in NHS Forth Valley; my membership of the Neurology Waiting Times Task and Finish Group; and my chairing of the periodic review of the Scottish Acquired Brain Injury Managed Clinical Network. I draw, largely, on examples from NHS Forth Valley, because that is the service with which I am most familiar, but I am sure that there are many other examples of good practice elsewhere on which I could have drawn.

1. 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?
   a. For the purposes of this response I have taken the definition of prevention given in 6.1 of the Christie Report, viz. “preventative spending, which seeks to prevent problems before they occur”
   b. The response rests, then, on whether neurological conditions are preventable (we could stop them from occurring in the first place); whether the disability and handicap which is caused by neurological impairment is preventable; and whether in our public services (particularly but not exclusively health and social care) there is expenditure which is preventable.
   c. Are neurological conditions preventable? The marked decline in age adjusted stroke mortality in Scotland seen since about 1960, and the more recent decline seen globally in the age adjusted incidence of Alzheimer’s disease, suggests that changes in population health (likely related to management of blood pressure, reduced smoking and better access to primary care) is having some effect; in my view further actions to improve population health and reduce deprivation, probably best targeted at the very early years of life, are likely to be helpful. For non-degenerative neurological conditions, the evidence for avoidable causes is less direct, with the exception for instance of the impact of seat belt legislation on the incidence of head injury and post traumatic epilepsy. Legislation for minimum pricing for alcohol can also be seen in this context, as excessive alcohol intake is involved in a number of neurological conditions including head injury, epilepsy and dementia.
   d. Is the disability and handicap which is caused by neurological impairment preventable? One of the striking aspects of neurological disability and handicap is the variability in the extent to which a neurological impairment (a weakness or dysfunction of the nervous system) impacts on neurological handicap (a resulting limitation in a
person’s role in life). Reasons for this variability are not clear, but are likely to include external factors (wealth; family, social and professional support; rurality) and internal factors (including “resilience”). Some external factors are clearly amenable to government input, and preventative societal approaches which might enhance resilience take us back to early years education.

i. The aspect here which is most immediately relevant to the provision of neurological services is that of professional support. This encompasses firstly timely access to information about the neurological condition (diagnosis, information about the cause, information about the likely prognosis: most commonly provided in primary care, with a small proportion of patients ever being referred to a consultant neurologist); and secondly ongoing support (which for patients with major ongoing needs may be provided by a specialist nurse). Capturing clinical activity in primary care is difficult, and would be greatly assisted by incorporation of Community Health Index (CHI) tagging of activity in primary care such as GP consultations and District Nurse visits.

ii. Importantly, specialist nursing provision has conventionally been provided by “disease specific” specialist nurses, which has led to an inequality in that the amount of support available to a patient depends not so much on their need for support as on whether they are lucky enough to have a diagnosis where specialist nurses exist. The caseload of specialist nurses also varies substantially from condition to condition, and this is not always a reflection of differences in the amount of support required.

iii. Much of the support provided relates to for instance the need for home adaptations, rehousing, or eligibility for greater assistance, and while specialist nurses work well across the Health – Social Care boundary, the extent to which local government has been able to engage with for instance local planning of neurological services has, in my experience, been limited.

iv. Capturing activity across the Health-Social Care boundary is challenging, and would be greatly assisted by incorporation of Community Health Index (CHI) tagging of Social Care activity.

v. In some situations (for instance patients with minor head injury), it may be that early follow up with a neurologist or specialist nurse might be able to identify those who might benefit from further intervention to prevent later morbidity.

vi. Equally, while it might be argued that a waiting list to see a neurologist routinely is not a problem if urgent patients can be seen more quickly, this does not take into account for instance the health related anxiety which may occur in some people while waiting to be seen, or the handicap that comes from being advised not to drive until expert review, and how this can impact on quality of life.

vii. To the extent that stroke is a neurological condition, acute treatment with thrombectomy is highly effective in selected patients, and would represent a fine example of preventative spend, with a cost per quality adjusted life year of around £7000. Thrombectomy services have yet to be introduced in Scotland, despite the
e. **Is there “neurological” expenditure which is preventable?** Most identifiable neurological activity, in secondary care at least, is provided in an outpatient setting.

i. To the extent that inpatient care or emergency department attendances are unplanned, these might be reduced somewhat by preventative expenditure. For instance, having rapid access for the patient to a specialist nurse, and rapid access for a primary care physician (GP) to advice from a consultant neurologist, might obviate the need for some of these admissions or ED attendances. To that extent, these patient interactions might be seen as a failure of management in the community. Similarly, increased investment in and better organisation of our own neurology service in Forth Valley have in recent years led to a substantial (~75%) reduction in our use of beds in the regional neurology service without requiring the provision of a specialist inpatient service in Forth Valley.

ii. Provision of Neurology Consultant and Neurology Specialist Nurse WTE continues to fall short of benchmarking standards, and this means we do not have the human resources to contribute maximally to preventing unplanned admissions or emergency department attendances.

iii. Similarly, timely access to neurological expertise in the Emergency Department might obviate the need for hospital admission, and timely access to neurological expertise in the acute medicine setting might shorten hospital admissions. Such resources are available in some places—for instance in Forth Valley the median delay from referral to a neurological consultation in the inpatient setting is around 2 hours—but they are not widespread.

iv. In the outpatient context, most if not all neurology services in Scotland struggle to meet performance targets both for urgent and routine new patient referrals, and delays for return (follow up) appointments are unmeasured. Indeed, because doctors are likely to adjust the frequency of follow up visits in light of their evolving understanding of system capacity, any measurement is likely to be an underestimate of the true unmet need. The same may be true of referrals from primary care, with GPs electing not to refer some patients where the potential benefits of a neurological consultation are in their view moderate, because of the effect that referral would have on the speed with which their other referrals would be seen.

v. In some cases, preventative resource allocation has clear benefits. For instance, the establishment of a specialist clinic in Forth Valley for patients receiving intravenous Immunoglobulin led to a concentration of expertise and of focus, and savings in prescription costs of around £160k p.a.. However, this came at the expense of new routine outpatient activity.

vi. Provision of additional neurology new patient out-patient capacity is required on an ongoing basis in most boards, either from internal waiting list activity or external (commercial) activity provided either
on own premises or in private hospitals. External waiting list activity is generally an expensive approach, not just in terms of the up-front costs but also (in our local audit) in increased rates of investigation, generation of complaints, reduced knowledge of local services and the need to transfer to a local neurologist where follow up is required. Preventative spending on increasing recurrent capacity would be cost saving, but since these funds come from a different budget source this has proved difficult to implement at a local level.

vii. Related to this is difficulty in recruiting to Consultant Neurology posts in Scotland even when these are funded. The chart shows the percentage of the whole time equivalent consultant neurology compliment which was unfilled in September of 2010 to 2017. This is largely a failure to increase consultant numbers, and reflects a difficulty in increasing capacity even when posts are approved. There are a number of possible reasons for this.

![Graph showing percentage of consultant neurology posts unfilled from 2010 to 2017.](chart.png)

2. Is the approach adequate or is more action needed?
   a. Given the commentary above, it is my view that more action is needed. Such actions might include, but are not limited to, the following non-mutually exclusive approaches
      i. Interventions at the societal level to increase healthiness, reduce deprivation, increase early years education and to minimise avoidable harms.
      ii. Interventions in Health and Social Care to ensure better professional supports for patients with neurological impairments, including the ability to collect person-level data (through CHI linkage) across the Health and Social Care boundary.
      iii. Discontinuation of external (commercial) waiting list activity, with funds diverted on recurrent basis to local NHS services
iv. Increased provision of nursing (Specialist nurse) and medical (Consultant neurologist) capacity, with expectation that this will be generic (i.e. available to all patients) rather than provided for particular diseases.

v. Efforts to improve recruitment and retention to the medical and nursing workforce.

vi. Increased recognition for clinical activity beyond the neurology inpatients and outpatient work captured in SMR00 and SMR01, to include inpatient liaison work, availability for consultation with other health care professions in primary and secondary care, ad hoc patient contacts using email, telephone, etc.

3. Are the services for neurological conditions being measured and evaluated in terms of cost and benefit?
   a. **Cost**: Because so much of the burden of neurological conditions falls on patients, unpaid carers and in primary care, costs are difficult to ascertain. Without measuring activity in primary care, where the bulk of services are delivered, or partitioning the costs of in patient activity in settings other than neurology units (which form a minority of the inpatient care of people with neurological conditions), even ascertaining the true costs to the NHS is difficult. It may be that we have to be content with measuring “Neurology services” rather than “services for neurological conditions”, while recognising the limitations of this approach. Some sampling of patient experience (following a patient through their contacts with health and social care) may provide useful qualitative information against which the more focussed quantitative data from neurology services may be contextualised.

   b. **Benefit - Outcomes**: Measurement might occur through consideration of process or of outcome. In some contexts it might be possible to seek evidence for unexplained variation in for instance mortality rates for patients seen in Neurology clinics; or Emergency department attendance rates for patients with a diagnosis of epilepsy. However, these have limitations in that it is not clear how much these outcomes might be influenced by the services provided, and the time interval between the neurology service input and the outcome being measured might be so long as to be of limited use for either accountability or for improvement.

   c. **Process based audit**: Some audit systems measure the benefits of a service indirectly. For instance, the Scottish Stroke Care Audit does not measure recurrent strokes, but rather that processes known to reduce the risk of recurrent stroke or to improve outcome have functioned as intended. Indeed, to the extent that stroke is a neurological condition, process based audit performs well. However, it is interesting to note that, even with such a system in place, the NHS in Scotland has not to date been able to introduce a new, highly effective, well evidenced treatment (thrombectomy).

Some evaluation of this kind does occur, but more might be feasible, for instance:
i. What is the waiting time from referral for a specialist opinion to response for neurology outpatient services. This should include any delay from the patient being seen to the referring doctor, and ideally the patient, receiving written communication about the outcome of the consultation?

ii. What is the interval from an inpatient being referred for a neurology opinion to their being seen by a Consultant Neurologist (or equivalent of a doctor in training acting under their supervision) or the referral being closed in a different fashion (e.g., decision to offer outpatient appointment)?

iii. What proportion of women of childbearing potential receiving a prescription for sodium valproate have documented evidence that they have received advice about the risks of valproate to the developing baby?

iv. What proportion of patients with suspected motor neuron disease in whom a neurophysiological examination is requested have this performed and reported within 14 days?

v. What proportion of patients with epilepsy have an ECG documented at or before their first neurology clinic visit?

vi. What (e.g., using the CARE questionnaire) is the opinion of the patient about the neurology consultation which they have had?

vii. What are the waiting times for neurophysiology; brain imaging; video telemetry (applies to regional services only)?

In my view, there should be a small number of audit items, changed or rotated over time, and wherever possible collated from datasets already available. Where this is not possible, it is likely that some form of support for audit data collection would be required.

Thank you again for the opportunity to comment. My conflicts of interest include membership of the UK MHRA Commission for Human Medicines; of the UK Home Office Animals in Science Committee; I have received grant funding from Wellcome Trust, MRC, NC3Rs, Laura and John Arnold Foundation, EU FP7 program, EU IMI program, and CSO. I am academic coordinator of the IMI EQIPD consortium, which includes Janssen, Abbvie, Boehringer, Novartis, Orion, Pfizer, Psychogenics, Roche, Servier, UCB and Sanofi. Occasionally I do internal waiting list clinics in NHS Forth Valley at the request of our waiting times office.

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