

**c/o MND Scotland**

**2 City View**

**6 Eagle Street**

**GLASGOW**

**G4 9XA**

8 February 2019

To whom it may concern,

**Re: Response to the Consultation on the National Action Plan on Neurological Conditions**

The Neurological Alliance of Scotland is an umbrella body of organisations and groups representing people living with or affected by a neurological condition. Together we enable neurological organisations/groups to campaign together and speak with an influential voice.

As you will know we have been involved in the process of drafting the National Action Plan and helped bring together voices from across the neurological community through engagement events with the Scottish Government. We commend the inclusive approach the Scottish Government's has taken in drafting this plan, including the structure of the project team and engagement events. We look forward to this approach continuing through the rest of the process.

We have been keen to engage with the development process and welcome this opportunity to comment further on the plan. We welcome the introduction of the plan and believe that if it achieves its potential it can have a transformative effect on the care and support provided to people living with neurological conditions in Scotland.

Many of our members have indicated they will respond individually to the consultation, we hope you find these comments useful and will consider all our members’ views when analysing the consultation responses. Our members support and advocate for the neurological community every day and have a clear understanding of the needs of people with neurological conditions in Scotland. We would encourage the Scottish government to trust and incorporate their views where possible.

Our response focussed on five overarching questions we posed to our membership and executive and enabled us to produce the summary of comments stated below. We are keen to reiterate that there is broad support for the National Action Plan and that people have felt encouraged by this renewed focus on neurological conditions from the Scottish Government.

 **Q1: Is there anything not contained within the action plan that you think should be addressed?**

* Our membership displayed overwhelming support for the principles of the action plan. There was concern raised about the lack of measurement instruments included within the plan and minimal reference to the General Standards for Neurological Care and Support which are currently being reviewed. It was felt that without a clear reporting process the potential of the plan would not be fully realised and that it would lack the authority needed to drive change.
* It was felt that there should be greater recognition that people with neurological conditions live in many and varied locations and situations and that this plan needs to be explicit in accommodating everyone regardless of their circumstance. In particular there needs to be reference to specialist neurological care within a care home or residential setting.
* As this work reaches across the spectrum of neurological conditions there has been significant concern raised that the role of condition specific services and specialists is being underplayed. The role of specialist nurses for example is vital in the successful delivery of care and support to people living with a range of specific neurological conditions. We want to ensure that a generalised plan does not erode their central role within neurological services in Scotland. We would welcome the Scottish Government being more explicit in how it intends to secure these roles and specialisms within this plan and future service provision
* The role of specialism extends beyond specialist nurses and neurologists and it was felt this should be recognised in the plan, right across the multi-disciplinary teams. In particular neuropsychiatry, speech and language therapists and specialist physiotherapy were discussed as an underserved areas at present. It was agreed that at present there is little consensus as to what constitutes a multi-disciplinary team.
* People felt that palliative care and mental health were not adequately contained within the plan. Whilst these may be covered by other Scottish Government action plans it is important to note that people with neurological conditions can often face unique circumstances that may not be covered within those plans.
* Whilst there was some reference to regional planning it was felt this was broadly missing – in particular how people access specialist services where these do not exist within their health board area. Reference should also be made to the Scottish Government’s drive towards community care and away from care in an acute setting.

**Q2: Is there anything contained within the plan that you think should be removed?**

* No, it was felt that everything already included within the plan provided an excellent starting point for improving care and support for people living with neurological conditions in Scotland.

**Q3: Is there anything contained within the plan that you think should be changed/improved?**

* The narrative contained within the document sets out a clear ambition for what the Scottish Government wants to achieve. However, it was felt that this wasn’t always reflected in the commitments. As such we would be keen to see this ambition reflected in the commitments throughout the plan.
* There needs to be greater clarity on how this will relate to the General Standards for Neurological Care and Support.
* It was felt there was an opportunity for a more explicit commitment to exploring the range of definitions and approaches to self-management. A number of organisations deliver self-management and are funded variously by internal and external funding. It is important the Scottish Government considers all self-management models and draws on the experiences from across the sector.
* Monitoring and reporting mechanisms would demonstrate how successfully the plan is being delivered.
* As mentioned previously it is important that the needs of individual conditions are not lost within the broader conversation around neurological care and support. We would welcome additional mention of condition specific specialists and the vital role they play in support and care.
* There was widespread support for the proposal to create rapid access neurology clinics and open access clinics for Epilepsy. It was welcomed that there was a specific mention of epilepsy due to the need for quick diagnosis of this conditions. We believe that other neurological conditions would benefit from equally swift approach to diagnosis - for example relapsing MS whereby early treatment significantly improves the individuals’ prognosis for their condition. We would welcome discussions with the Scottish government to see how this innovative idea could be expanded further. As part of this discussion we would want to ensure that the introduction of rapid access clinics for some conditions would not have a negative impact on access for other conditions. The role of rapid access clinics should allow people with a neurological condition to be able to access the services they need when they need it, reducing the wait for a lengthy referral process.
* The issue of workforce is mentioned in commitment 16 and it was felt that there needed to be a more realistic discussion about the current and future workforce needs. It is well understood that there are significant ongoing vacancy levels for neurologists, currently around 10% with a significant numbers of these being vacant for more than 6 months, and little in terms of forward planning to fill these gaps and create a sustainable workforce. This is by no means unique to neurologists and can be seen across a range of specialisms and the broader workforce including specialist AHPs, specialist nurses, neuro psychiatrists and psychologists, and others. There is significant distance to go in order to meet current need so the Scottish Government has to be realistic about how it aims to meet the potential additional need that the implementation of this plan brings. In reality there needs to be greater investment in this area, not only in simply numbers of professionals but in terms of training, recruitment and retention. Training of primary care Physicians and AHPs to support continued care delivery will also drive improved efficiencies. We would welcome the opportunity to discuss this further with the Scottish Government and would welcome any approach that would lead to a more sustainable workforce
* The plan needs to have an improved understanding of the strength of the third sector and what it can offer and deliver for people living with neurological conditions. For example, commitment 6 references the third sector but we would want the third sector to be seen as a core partner not as an add on. This potential of the third sector, if financially sustained, to drive improvements in services and care, needs to be better understood by the NHS and health and social care partners. .

**Q4: Overall, do you think the commitments contained within the plan will deliver the Scottish Government's vision for people with neurological conditions?**

* The Scottish Government has set a powerful vision for the National Action Plan and we welcome, and are encouraged by, this level of ambition. We believe what is contained within the action plan, if fully implemented, takes us much closer to this vision than is currently possible. It provides a useful starting point and we hope that, as the consultation continues, this can be built upon and strengthened to ensure the action plan will deliver the Scottish Government’s vision for everyone living with a neurological condition in Scotland.

**Q5: Do you have any other comments you wish to make about the Action Plan?**

* In order to have successful implementation this plan needs clear leadership and governance. There is a need to have clear ownership and accountability for delivery – much of which relates to the previously raised issue of the need for clear and comprehensive monitoring and evaluation.
* We recognise the challenge that the Scottish Government faces in working across the public sector in order to deliver this plan, in particular across Integration Joint Boards. It is a wide reaching plan that impacts on many agencies and services. However, it could also be a ground-breaking piece of work if it can demonstrate joint working and break down barriers - real or perceived - that currently exist.
* We believe that Scotland is a world leader in research into neurological conditions and as such welcome the commitment the plan gives to supporting the neurological research agenda in Scotland.
* Finally, we welcome the commitment in the plan to address the issues around accurate prevalence and incidence data for neurological conditions.

We hope you will find these comments useful and we look forward to continuing to play a central role in the design and delivery of the National Action Plan.

Yours sincerely.

**Gerard Gahagan**

**Acting Chair, Neurological Alliance of Scotland**

**cc. Colin Urquhart, Policy Team Leader, Clinical Priorities, Scottish Government**