

Response ID ANON-V2XP-WNXF-K

Submitted to **A consultation on the draft National Action Plan on Neurological Conditions (2019-2024)**

Submitted on **2019-02-07 18:14:32**

Our Vision, Scope and Approach

1 Everyone with a neurological condition will be able to access the care and support they need to live well, on their own terms.

Yes

2 Do you agree with the decision to maintain a broad view of neurological conditions rather than include every neurological condition by name in the plan?

No, I disagree

3 There is separate work by Scottish Government considering how best to support children and young people with disabilities and their families, so we decided to consider the needs of people who are 16 years and older in the plan.

Yes, I agree

4 Developing the National Action Plan involved a range of activities to make sure we identified the right priorities. Do you think we included the most important priorities in the plan?

No

5 If you would like to make any comments in relation to any of the questions above, please do so here.

If you would like to make any comments in relation to any of the questions above, please do so here: :

Regarding Q2 SPPC believes that there is a middle ground between the totally generic and naming every neurological condition individually. The plan rightly recognises the huge diversity of neurological conditions and the variety of related needs and impacts. It would make sense for specific programmes of work to address the specific conditions or perhaps sub categories of disease likely to share common issues. We would hope to see this in the more detailed implementation plan. Some types of service require a specialism in a particular condition.

Ensure people with neurological conditions and their carers are partners in their care and support

6 Aim A

Yes

7 Commitment 1

Yes

8 Commitment 2

Yes

9 Commitment 3

Yes

10 If you would like to make any comments in relation to Aim A and Commitments 1 - 3, please do so here.

If you would like to make any comments in relation to Aim A and Commitments 1 - 3, please do so here: :

SPPC supports Aim A and welcomes commitments 1-3.

Respite care is a vital support for carers, enabling them to maintain their own health, prevent crisis and to be able to continue to provide care, particularly for people with advanced neurological conditions. SPPC would like to see an explicit commitment to improving access to respite care, including age-appropriate residential respite care. SPPC would also like to see consistent national eligibility criteria to determine funding for respite care.

Improve the provision of co-ordinated health and social care and support for people with neurological conditions

11 Aim B

Yes

12 Commitment 4

Yes

13 Commitment 5

Not Answered

14 Commitment 6

Yes

15 Commitment 7

Yes

16 Commitment 8

Yes

17 Commitment 9

Yes

18 Commitment 10

Yes

19 If you would like to make any comments in relation to Aim B and Commitments 4 - 10, please do so here.

If you would like to make any comments in relation to Aim B and Commitments 4 - 10, please do so here: :

SPPC welcomes aims Aim B and commitments 4 - 12.

In respect of commitment 4 SG should use the powers under the Carers Act to review local eligibility criteria, and move towards national criteria. It is hard to reconcile aa commitment to reducing inequality and variation with the current system where there are 32 different sets of eligibility criteria.

In respect of Commitment 9 SPPC welcomes the emphasis on anticipatory care planning processes. Progress in this area will require an investment in training and development of staff, adequate clinical time to engage in discussion, and significant progress on the national digital platform so that ACPs can be accessed and updated across settings by different staff and by people with neurological conditions.

Paragraph 38 has a serious omission. There is a welcome emphasis on maintaining independence, health and wellbeing. However the paragraph (indeed the whole plan) fails to recognise that many people will die with and/or as a result of a neurological condition. People with advanced neurological disease are likely to have the greatest levels of need and complexity (and likely incur high resource use) yet this phase of disease goes un-noted in the plan.

In respect of commitment 9 SPPC welcomes the exploration of new generic models. We would also caution against the dilution of specialist condition-specific expertise. It is not realist for a CNS (for example) to maintain adequate expertise in lots of diverse neurological conditions.

Ensure high standards of effective, person-centred, and safe care and support

20 Aim C

Yes

21 Commitment 11

Yes

22 Commitment 12

Yes

23 Commitment 13

Yes

24 If you would like to make any comments in relation to Aim C and Commitments 11 - 13, please do so here.

If you would like to make any comments in relation to Aim C and Commitments 11 - 13, please do so here.:

SPPC supports Aim C and commitments 11-13.

SPPC acknowledges the complexity of achieving meaningful measurement. We suggest that seeking feedback directly, consistently and systematically from people with neurological conditions and their families will be a useful approach. Feedback should not be structured around specific services, but rather ask people

about their experience across the system so that issues around transitions and inter-institutional interfaces are properly identified - and those institutions required to respond collectively with agreed solutions to recurrent issues.

Improve equitable and timely access to care and support across Scotland

25 Aim D

Yes

26 Commitment 14

Yes

27 Commitment 15

Yes

28 If you would like to make any comments in relation to Aim D and Commitments 14 - 15, please do so here.

If you would like to make any comments in relation to Aim D and Commitments 14 - 15, please do so here: :

SPPC supports this aim and commitments

Build a sustainable neurological workforce fit for the future

29 Aim E

Yes

30 Commitment 16

Yes

31 Commitment 17

Yes

32 If you would like to make any comments in relation to Aim E and Commitments 16 - 17, please do so here.

If you would like to make any comments in relation to Aim E and Commitments 16 - 17, please do so here: :

SPPC supports Aim E and commitments 16-17

Implementation of the plan

33 We want the plan to be implemented successfully and to be able to measure success.

Please provide comments or suggestions on the implementation of the plan here::

SPPC supports the thrust of the plan, the aims and the commitments contained in the plan (with the few caveats placed in the text boxes). The plan demonstrates a welcome scale of ambition for a group of people whose circumstances have historically been relatively neglected and underfunded, perhaps because the medical profession have had (in many cases) relatively little to offer by way of curative interventions. But whilst major advances to prevent and cure neuro-degenerative conditions are still awaited there is no reason why people should have to experience long waits for a wheelchair service or their carers have shrinking access to high quality respite care.

We welcome the proposed infrastructure at national level to take forward implementation. A lot of the commitments are very high level and non-specific. We look forward to seeing the implementation plan and the translation of these commitments into deliverables which can be measured, and through which people with neurological conditions will be able to hold the system to account at the end of the 5 year implementation phase.

SPPC recognises that many of the aims in the plan are dependent on wider generic workstreams for their achievement (e.g. development of social care workforce, development of national digital platform). We recognise the challenge of delivering this plan in the context of current financial pressures and workforce limitations (both of which are likely to be exacerbated if Brexit proceeds).

34 What is the most important thing we need to change to improve the NAP?

What is the most important thing we need to change to improve the NAP:

SPPC would like to see the plan link to the aims and outcomes of the SG Strategic Framework for Action on Palliative and End of Life Care (not just reference the ACP work).

People with advanced neurological disease who are approaching the end of life often have high very levels of need, poor prognosis, have poor access to primary and secondary healthcare, and are charged for basic care, often in age-inappropriate residential social care settings. There is huge scope for improving the circumstances of this phase of illness. Work has been done in England to develop pathways which achieve earlier integration of palliative care services and

approaches. We would like to see these developed and tested during the implementation period.

35 If you have any other comments or suggestions please make them here.

If you have any other comments or suggestions please make them here: :

About you

What is your name?

Name:

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What is your email address?

Email:

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Are you responding as an individual or an organisation?

Organisation

What is your organisation?

Organisation:

Scottish Partnership for Palliative Care

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

Publish response with name

We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Yes

Evaluation

Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:

Very satisfied

Please enter comments here.:

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?:

Very satisfied

Please enter comments here.:

It would be able to view a draft editable version of one's response just before submission (just to be able to read it over quickly and correct minor errors/check for coherence). Rather than have to navigate around all the questions again.