

Response to Scottish Government's Submission of 12 July 2018

1. Introduction

In the Scottish Government's submission of evidence in response to #MEAction Scotland's petition, it references Scotland's first National Action Plan (NAP) on Neurological Conditions, asserting that the recommendations made in this plan will address the needs of people with myalgic encephalomyelitis (ME) in Scotland. The NAP was published in December 2018, and, having reviewed the plan, we submit that it does not address the needs of people with ME.

The NAP was developed by the National Advisory Committee on Neurological Conditions (NACNC) which, according to the Government's submission, was established as part of policy developments "*to improve the way services are delivered for people living with neurological conditions, such as ME*". The Scottish Government states in its evidence that the NACNC aims to "*drive improvements in the care, treatment and support for people living with neurological conditions across Scotland*".

Note: the NAP is not condition-specific, but is designed to offer a strategy focussed on supporting all adults with a neurological condition.

2. Summary

Overall the NAP does not address the current situation relating to support and treatment of people with ME in Scotland. It sets out 17 commitments that it claims will ensure people living with neurological conditions have access to the best possible care and support. People with ME were excluded, however, from the two key pieces of work commissioned to underpin the report: the report on the prevalence of neurological conditions and the mapping of neurological services. Without this information the Action Plan cannot address the needs of people with ME. Furthermore, recommendations in a third piece of work commissioned by the NACNC relating to the development of services for people with ME have been ignored. We summarise the key points in our submission in this section, with sources for the evidence cited given in Section 3: Background and Evidence..

We ask the Scottish Government how it can develop a plan which includes people with ME when it has no data on the patient population and their use of services?

- The NAP does not acknowledge that ME is excluded from the data on prevalence of neurological conditions. As ME is not included in the data collection on the prevalence of neurological conditions in Scotland, it is also excluded from the findings on the use of NHS Services.
- It is estimated from other sources that there are 21,000 people in Scotland with ME: meaning that it is twice as prevalent as multiple sclerosis (MS) or Parkinson's¹. This is illustrated by the high response rate from people with ME to the Lived Experience Survey commissioned by NACNC: 33% of responses to the survey were from people with ME.

¹ Nacul, L (2011), Prevalence 0.2-0.4% of population in three regions of England: a repeated cross-sectional study in primary care, *BMC Medicine*, 9:91.

We ask the Scottish Government how it can develop a policy which claims to include people with ME, based on data on current use of neurological services, when neurologists have so little understanding of ME and patients are excluded from using current services?

- The report on the NACNC's Lived Experiences survey confirms the lack of understanding of ME amongst healthcare professionals and identifies an acute lack of services. The report's recommendation on how to address this are ignored in the NAP.
- Not only are people with ME excluded from the data collection and the reports that inform the plan, but neurologists in Scotland do not believe that ME is a neurological condition and patients are actively excluded from using neurological services.
- There is a lack of understanding amongst healthcare professionals that ME is a neurological illness, as evidenced by survey findings that over 80% of neurologists do not believe it is a neurological illness .
- There is also anecdotal evidence that patients are being refused treatment by neurology departments (see details below).
- The NAP does not acknowledge the lack of services for people with ME: it focuses on improving current services, making no commitments for neurological conditions where services simply do not exist or patients are denied access to them.

We ask the Scottish Government how it can claim to support people with ME effectively when the clinical nurse specialist role that it describes as “*pivotal*” exists only in one health board area?

- The evidence submitted by the Government says that *“in terms of specialist care we recognise the role of the clinical nurse specialist is pivotal in delivering integrated services”*.
- We are aware of a precedent to provide ring-fenced funding for specialist nurses for people with specific conditions (MND) and we urge the Government to consider doing this for people with ME.
- The lack of data on ME and lack of support for patients underscores our petition demand that there should be a comprehensive review of the level of support for people with ME in Scotland, with a view to investing in research, education and care for people with ME.

3. Background and Evidence

The NACNC commissioned several pieces of work in drawing up the Plan and say that they have used the findings to develop the Vision and Aims of the plan. We have identified a number of issues in the work commissioned which means that the needs of people with ME will not be met through the NAP. We summarise these issues below.

Lack of Data on Prevalence of ME in Scotland

- An investigation by the NHS Information Services Division into the **number of people living with different neurological conditions in Scotland and data on the use of NHS Services**. The report identified the prevalence of common neurological conditions, but did not include ME as there is no record kept of the illness by NHS Scotland. The table from the report is shown in Appendix A of this submission - illustrating that ME, despite being estimated to be more prevalent than MS or Parkinson's disease, is excluded from official statistics. As a result, there is no data on ME on which to base the plan and the proposed development of services.

ME is misunderstood by neurologists and ME patients are excluded from neurological services

- A survey '**Mapping Neurological Services in Scotland 2017/2018**'. According to NAP this survey "*identified current care and support services and existing gaps in provision*". We know from the evidence submitted by NHS Lothian in response to our petition that 84% of neurologists in Britain do not think that ME is a neurological condition². In addition, we have anecdotal evidence that patients with ME are being refused treatment by neurological departments in Scotland, as this quote from a letter sent by a Scottish neurology consultant to a GP in December 2018 illustrates:

"I have received your referral regarding this lady and her diagnosis of ME and request to see an ME specialist. I am afraid we have taken the decision in neurology here that we do not see referrals of suspected chronic fatigue syndrome / ME in the absence of concerning neurology symptoms or signs. None of the neurologists in [neurologist's health board area] have any particular expertise in managing chronic fatigue syndrome so I am afraid I do not think we would be able to help this lady. I appreciate this is not very helpful for you and I am not sure what else to suggest. I know the situation is similar within Edinburgh neurology."

- The '**Priorities from the Lived Experiences Project**' report on the findings of a survey commissioned by NACNC, confirms the lack of understanding of ME amongst healthcare professionals and an "*acute lack of services*"³. The survey findings are significant as 33% of the 578 responses were from people with ME. The report also includes a recommendation that the Neurological Action Plan explores ways of laying the foundations for care pathways for neurological conditions, like ME, where services do not exist⁴. These points are ignored in the Action Plan.
- Our petition highlights the serious need for education of healthcare professionals. The fact that ME is not recognised as a neurological condition by neurologists and, therefore, patients are excluded from current neurological services, confirms that action needs to be taken urgently.

ME patients have no access to clinical nurse specialists

- The Government's evidence submission to the Petitions Committee states "*In terms of specialist care we recognise the role of the clinical nurse specialist is pivotal in delivering integrated services focused on prevention, early intervention and enablement to support people and their families....*". The survey commissioned by the NACNC shows that no such

² NHS Lothian did not provide a source for the survey, but we have found that the survey was of members of the Association of British Neurologists in 2011 and the results were reported in the Journal of Psychosomatic Research, April 2011

<https://www.sciencedirect.com/journal/journal-of-psychosomatic-research>

³ Priorities from the Lived Experiences Project report - page 28: "*One of the notable results was the difference in access to services across condition groups and resulting health inequalities. Whereas some conditions have established specialist support, patients with ME and rare conditions, reported a particularly low rate of understanding amongst professionals and an acute lack of services.*"

⁴ Priorities from the Lived Experiences Project report - page 8: Recommendation: "*Development of an action plan to explore how foundations for care pathways can be laid in areas where services are still to be developed.*"

provision is available for people with ME. We call on the Government to provide ring-fenced funding for clinical nurse specialists to the health boards in order to ensure that patients with ME have access to this specialist service.

- The ‘Mapping Neurological Services in Scotland 2017/2018’ survey report highlights the number of clinical nurse specialists for neurological conditions in Scotland. The table below shows the number of nurses compared with the patient population which is listed in Appendix B of the main Plan. This shows the number of specialist nurses available for neurological conditions such as Multiple Sclerosis (24.05 nurses), Parkinson’s (18.79) and Motor Neurone Disease (9.55). We have added ME to the table so that comparisons can be made: there are estimated to be 21,000 people with ME in Scotland, with only one specialist nurse (in Fife).

Table 1: Prevalence of Neurological Conditions and Number of Specialist Nurses

Neurological Sub-specialty	Total population in Scotland SBOD prevalence⁵	Total clinical nurses by Sub-specialty⁶
Multiple Sclerosis	9,700	24.05
Parkinson's Disease	12,600	18.79
Epilepsy	43,100	15.46
Motor Neurone Disease	730	9.55
Headache	n/a	2.00
Myasthenia Gravis	n/a	2.00
Dystonia	n/a	2.20
Other*	n/a	8.55
<i>ME</i>	<i>21,000**</i>	<i>1.00</i>

* Brain Injury Rehab/Astley Ainslie/Programmed Investigation Unit/Acute Neurology, NHS Lothian

** estimated from research demonstrating ME affects 0.2-0.4% of the population in three regions of England

⁵ *Scottish Burden of Disease study, 2015*. NHS Health Scotland and NHS Information Services Division

⁶ *Mapping Neurological Services in Scotland 2017*. National Advisory Committee for Neurological Services (report not published)

- The submission of evidence from the Government states that *“the Scottish Government has invested an additional £2.5 million annually in specialist nursing and care”*. As the table above illustrates, the funding is certainly not being directed to clinical nurse specialists for people with ME. The additional £2.5 million included £700,000 ring-fenced funding for MND nurses⁷ and we believe that a similar funding commitment should be made to ME patients, with the amount of funding proportional to the the patient population.
- Our petition asks for increased access to and investment in care for patients with ME: the NAP highlights how important this is for neurological conditions. By excluding ME from key data sets and ignoring the findings of the Lived Experience Survey the NAP does not address the lack of support and care for people with ME.

⁷ <https://www.gov.scot/publications/report-specialist-nursing-care-fund/pages/1/>

Appendix A:

Table from NAP - Examples of common neurological conditions and prevalence in Scotland based on Scottish Burden of Disease project

Condition*	SBOD prevalence**
Alzheimer's disease and other dementias	66,300
Migraine	1,075,029
Tension Type headache	1,400,722
Epilepsy	43100
Multiple sclerosis	9700
Parkinson's disease	12,600
Motor neurone disease	730

*This list is not exhaustive and reflects limitations of current data.

***Scottish Burden of Disease study, 2015*. NHS Health Scotland and NHS Information Services Division