**Policy Group Meeting Agenda**

**24 February 2021**

**11am**

**Join Zoom Meeting**

  <https://zoom.us/j/97991296943>

Attendees:

Colette McDiarmid, MND Scotland, Chair

Tanith Muller, Parkinson’s UK

Rona Johnson, Epilepsy Scotland

Avril McClean, Action for ME

Jonathan Sher, QNIS

Paula MacGillivray, MS Society

Catherine Paterson, Dochas Fund

Gill Dickson, PSP Association

Alice Struthers, NAoS Co-ordinator

Apologies

Victoria Wareham, Dystonia UK

Alistair Haw, Scottish Huntington’s Association

Sue Millman, Ataxia UK

AGENDA ITEMS

1. Introduction and welcome
2. Increasing support for, and impact of, community nurses in relation to neurological conditions

**Discussion:** In order to increase the impact of community nursing we need to consider who else can support an individual living with a neurological condition. The issue is not a question of confidence in community nurses, but in sourcing skilled people from other backgrounds who can deal with people in the community living with neurological conditions, particularly for conditions without a medical pathway. Parkinson’s UK is interested in multi-disciplinary support. SHA have a team of charity-funded community nurses. PSPA have recently concluded a phase 1 neurological framework funded project in mapping services for PSP and CBD which looks into best models of care.

Furthermore, Action for ME and Parkinson’s noted the difficulty in dealing with National Education Scotland (NES) who refuse to engage on condition-specific neuro work.

**In conclusion,** NAoS would like to see a broadening of the community support model beyond nurses. We would like to see more engagement and co-operation from NES.

**Actions:** Gill Dickson (PSPA) to send NAoS their recent PSPA mapping report for distribution around the Policy Group.

1. Restoration of neuro services to pre-Covid levels

**Discussion:** Although the forced move to remote consultations through the covid pandemic has been largely successful, we do not want clinic time to be lost entirely once the pandemic has run its course. This is seen as a very real threat. In addition, we note that clinical services in a pre-covid world were already far from perfect.We have an opportunity to really think about what people need, both patients and clinicians, and to re-design neurology services entirely.

Reference was made to the [excellent debate on remote consultations held by the Neurological Alliance (England)](https://www.neural.org.uk/neuro-fest-november-2020-opening-debate/) which held very balanced views from both clinicians and patients.

**In conclusion**, NAoS should take the lead in re-designing neurology services in a post Covid world. We need to be pro-active about what building back better means. There are clear benefits to the use of virtual appointments however they are not suitable for all neurology patients all of the time. The NAoS would like to see research commissioned on the impact and consequences of remote consultations.

**Actions:** No actions at this stage.

1. Data on the number of neurological patients with a rare disease

**Discussion:** It is widely acknowledged that accurate neurological condition prevalence data does not exist, either in England or Scotland. Within Scotland, health boards do not even communicate between themselves. Key to improving services is knowing prevalence data - how can you build services without knowing the number of people affected by a condition? Both Action for ME and Epilepsy Scotland noted the lack of adequate recording of the number of people affected by these conditions.

Gill Dickson (PSPA) noted that the English Neurological Alliance published a report on rare diseases in November 2020 which the PSPA contributed towards.

The UK Government published a Rare Disease Framework on 9th January which the Scottish Government supports. [The Scottish Government will now publish an action plan by the end of 2021](https://www.gov.scot/publications/rare-disease-final-progress-report/pages/10/) reporting how it will implement the Framework taking into account the population needs and health system we have here in Scotland. Information from the link above includes the following paragraph:

*The UK Government’s Rare Disease Framework was published on 9 January 2021 to replace the existing strategy.*

*The Framework takes a 4 nation approach to supporting those living with a rare disease. The vision and objectives are based on stakeholder engagement and the results from the Rare Disease National Conversation survey. As we have done in previous years, Scotland will develop its own action plan setting out how we will implement the Framework taking into account the population needs and health system we have here in Scotland.*

*To do this we will establish a new Rare Disease Implementation Board to oversee the action plan. Further details will be in the Action Plan which will be published in 2021. Throughout the development of the Plan there will be many opportunities for the rare disease community to engage with us to help shape and inform the actions.”*

Catherine Paterson (Dochas Fund) added that looking into the impact of Covid on prevalence and outcomes (e.g. prognosis) of neurological conditions will be interesting.

**Conclusion:** Prevalence data is relevant both for structuring service provision and potentially for changing the direction of service offerings. Mental health post Covid is likely to have had a massive impact, with a potential reduction in lifespan of those living with neurological conditions.

**Actions:** Following the Policy Group meeting, we heard that the National Advisory Committee on Neurological Conditions is planning a piece of work to find out more about how many people in Scotland are identified as having a neurological condition and the NAoS will feed into this. The NAoS should also take the opportunity to feed into the Rare Disease Implementation Board throughout 2021.

1. Incorporation of the option of virtual appointments into the clinic appointments system (only when appropriate i.e. not at diagnosis stage) to give patients with stable but deteriorating conditions the option of a face to face consultation.

**Discussion:** This was covered in part by the discussion held on restoration of neuro services to pre-covid levels. Clearly, clinical commissioners will be keen to make savings where possible and there’s the danger that positive anecdotal evidence of the success of remote consultations will result in the overall loss of face-to-face clinical services. Before we lose essential services, we need to gather empirical evidence as to what is gained or lost by a broad shift to virtual appointments.

**Conclusion:** NAoS should advocate for a blended approach that meets the needs of both clinicians and patients. There is no one-size-fits-all approach that can work across the board. Action for ME pointed out that for patient centred care, you need to consult with patients as to what would suit them.

**Actions:** Can the NAoS gather evidence from patients about what would suit them and present it to the Scottish Government before decisions made to cut face to face appointments are made?

1. General Q&A

Tanith Muller (Parkinson’s UK) asked whether other organisations had heard of issues of people with neurological conditions being refused the Covid-19 vaccine on the grounds that they have a neurological condition. There have been many reports of this following a slight mis-interpretation of the Green Book being published and released to all health boards. Action for ME confirmed that c.50% of their helpline calls are about being refused the vaccine.

**Conclusion:** NAoS wants to build a picture of the scale of the problem.

**Actions:** Alice Struthers (Programme Co-ordinator) to ask all members to get in touch with their own anecdotal evidence.

1. Horizon scanning – what is coming up over the next two months

Dates for the diary:

NAoS Members Meeting: State of the Nation Update, end of March 2021, date TBC

NAoS Hustings 22 April, 1.30pm – 3pm

1. Next meeting date: 14 April 2021, 11-12pm  <https://zoom.us/j/94189174823>

Please note: Policy Group meetings are open to all NAoS member organisations.