**Policy Group Meeting Summary**

**12 January 2022, 11.00am**

**Attendees:**

Colin Robertson, Chair, Headway Dundee & Angus

Jackie Munro, MDUK

Gerard Anderson, CBIT

George Allan, SPPN

Carol Cochrane, Brainstrust

Sue Millman, Ataxia UK

Beth Strachan, CBIT

Kyla McDonald, Tourette Scotland

Anna Telfer, Epilepsy Scotland

Keith Park, MS Society Scotland

Jonathan Sher, QNIS

Colette McDiarmid, MND Scotland

Shirley Maxwell, Epilepsy Connections

Ewan Dale, ME Association

Gillian Robinson, MS Therapy Centre, Lothian

Leanne Creighton, Sue Ryder

Catherine Paterson, Dochas Fund

Claire Winchester, MS Trust

Alice Struthers, NAoS

**Apologies:**

Leigh-Ann Little, The Oxygen Works

Stephanie Fraser, Cerebral Palsy Scotland

Summary of the meeting

1. Chair’s welcome

Following an introduction from the Chair, Colin Robertson (Headway Dundee & Angus), everyone in the meeting introduced themselves.

1. Action points from previous meetings – follow up

During the September Policy Group meeting it was agreed that the NAoS should make the case for neurology services to be included in the NHS Recovery Plan, which is described as not being condition specific, but which has separate sections on cancer and mental health, as well as references to various ophthalmic conditions. Members of the Policy Group drafted a letter which was sent to the Cabinet Secretary on the 17th November and a response was received on 17th December which was shared with members via our Christmas newsletter and also sent directly as an attachment to members of the Policy Group.

The letter from officials sent on the 17th December includes this section:

*Work is being taken forward on education and training opportunities for Clinical Nurse Specialists (CNS) working in Neurology (and Multiple Sclerosis specifically) by a group including Scottish Government, NHS Education Scotland, MS CNS representatives and the NHS Centre for Sustainability Delivery. It will support Health Boards in recruiting and succession planning regarding these roles.*

George Allan, Scottish Post Polio Network (SPPN) asked what we can do to get CNS for people with PPS.

Keith Park, MS Society Scotland said that this work is being led by Judith Newton (Scotland’s Lead MND Nurse Consultant and Clinic Manager of the Anne Rowling Regenerative Neurology Clinic in Edinburgh) who is looking at the competencies of specialist nurses. The MS Society Scotland have been slightly involved.

Furthermore, the Scottish Government response says:

*As announced in the NHS Recovery Plan and by the end of 2021 we will publish a National Workforce Strategy designed around the strategic objectives which support remobilisation, recovery and renewal of Health and Social Care Services.*

As far as we know, the National Workforce Strategy was not published at the end of 2021.

Jonathan Sher, QNIS, flagged that since publication in August 2021, there has been very little said about the Women’s Health Plan which does not include neurological conditions. This may present an opportunity for NAoS to flag up with Scottish Government any distinctive ways that women are affected by neurological conditions, that may be addressed by the Neurological Framework for Action.

Alice then thanked those who helped with the NAoS Assisted Dying response which was submitted on the 21st December, particularly Stephanie Fraser (Cerebral Palsy Scotland) and Tanith Muller (Parkinson’s UK). The final response had to be made through a specific online portal, but for ease and for enabling engagement with members, we sent members a Word draft for comment in the week preceding submission. Our final response was distributed to members via the Christmas newsletter and is on our website under ‘News’.

The only outstanding action is that the NAoS hasn’t written to the Minister for Social Care, Kevin Stewart. This action arose following the National Care Service Consultation which closed in November 2021 (which NAoS submitted a response to – also available to see on

the News page of our website). The idea was that we would ask for action now rather than waiting five years for the establishment of a National Care Service.

Action: Policy Group members asked if we could invite Kevin Stewart to a future meeting, either a policy group meeting or a wider Members’ Meeting to have a better conversation about supporting care needs. Alice to draft an invitation letter.

1. PE1854/ - Review the adult disability payment eligibility criteria for people with mobility needs - update from MS Society Scotland

Colin Robertson invited Keith Park from the MS Society to give an update on the MS Society petition.

Keith explained that the petition essentially asks the Scottish Government to scrap the 20m rule when PIP transfers to Adult Disability Payment (ADP) in Scotland. ADP will be piloted in the Spring of 2022 with a view to being rolled out this coming summer. Following roll-out, there will be an ‘independent’ review in 2023 where opportunities to make changes will presumably happen.

The MS Society Scotland petition received over 3,000 signatures and closed on the 20th March 2021. The Petitions Committee wrote towards the end of last year to the DWP to ask whether there could be any consequences to passported benefits and the petition was considered again on the 17th November. It looks like passported benefits are being held as the reason for not scrapping the 20m rule. The NAoS was then asked on 19th November to explain whether we believed changes to eligibility criteria would risk passported benefits. We replied on 9th December saying that **we do not believe that changes to the 20m rule would impact on passporting to reserved benefits.**

Parkinson’s UK, the Citizen’s Advice Bureau, and NAoS have written in support of the petition.

MS Society Scotland is awaiting the next dates from the Petitions Committee, which are likely to be in February. They have cross party support and are asking for a debate to be held in Parliament. They also gave evidence just before Christmas to the Social Justice and Social Security Committee. Keith hopes to provide an update at our next Policy Group meeting in March.

1. Child Disability Payment – experiences so far?

There had been no feedback of any sort amongst members through their charities, of people experiencing difficulties with the new Scottish Child Disability Payment, which activated at the end of July 2021.

Action: If any members start to hear of issues with CDP, please flag it up and pass the info to Alice so the NAoS is aware if there are difficulties.

1. UK Govt - Acquired Brain Injury Bill/Strategy update

Colin Robertson invited Gerard Anderson (CBIT) to give the group an update as CBIT has been closely involved with the ABI Bill and now Strategy. Chris Bryant MP who is the Chair of the All Party Parliamentary Group (APPG) on ABI put forward this bill which had the sole intention of creating an ABI strategy for the UK (England/Wales and ideally through the devolved governments, to NI and Scotland too). Just ahead of the second reading on 3rd December, the UK Govt announced they would go ahead and create an ABI Strategy, which meant the second reading was no longer deemed necessary.

Chris Bryant MP and Gillian Keegan MP (Minister of State for Care) are now in the process of creating a board to work on the strategy with cross departmental Ministers. They would like involvement from individuals and charities across the UK including interested politicians and officials from devolved Governments.

The Board will be responsible for creating the template for the ABI strategy.

Currently it is called the ‘ABI and other neurological conditions strategy’, however the focus is very much on acquired brain injury. Related neurological conditions are anticipated to be included, for instance causes of ABI such as alcohol abuse, Parkinson’s, stroke or brain tumour. However, at this stage there is little information about how wide the strategy will be. It is thought that for it to be effective, it should retain a fairly narrow and deliverable scope.

The next steps are:

1. Chris Bryant MP and Gillian Keegan MP will create a board made up of people across the UK
2. A call for evidence – from people with lived experience and neurological charities or organisations
3. The board will use the evidence to complete the strategy
4. The intention is for the strategy to be in place by 2023

It was agreed that when it comes to the call for evidence, that it would cut noise and create more impact for the NAoS to put in a joint submission.

Sue Millman, Ataxia UK asked if other conditions such as Ataxia would be relevant. Ataxia is mainly genetic but it can also be acquired as a symptom of ABI. At this stage it is not

understood which neurological conditions may fall into the scope of the Strategy, and this will be determined during the call for evidence.

Actions:

1. Alice to share the CBIT response to the ABI Strategy *- done*
2. Please send Alice names of helpful, collaborative MSPs and officials you may know who could be involved in the UK ABI Strategy
3. If you would like to help with the NAoS submission, please get in touch with Alice. Ideally we’d have 3-4 members working on this. Keith Park, MS Society Scotland has offered to be part of this group. Keith will raise the ABI Strategy at the forthcoming MS Cross Party Group (CPG) to see if any MSPs are interested in being involved.
4. NAoS to put in a submission
5. Scottish Neurological Standards toolkit – what would it look like?

Unfortunately, we ran out of time to discuss this.

Action: Alice to get more information about what was meant by this suggestion (which came in via twitter).

1. A.O.B

Kyla McDonald, Tourette Scotland said that there are no SIGN guidelines for Tourette’s. It would be helpful to understand from larger charities how to start to influence change.

Jonathan Sher, QNIS suggested Voluntary Health Scotland as a good resource for this.

Alice, NAoS said this would be the sort of thing we could have at our next Knowledge Sharing Event, which is scheduled for 23 March. The idea behind these events is to provide informal learning platforms for members. We are thinking of having a panel-based event for the next one in March.

Actions: Policy Group members to send in suggestions and requests for the topics you’d find useful to learn about from other members. If you can offer training or support in any area, you can also nominate yourself to sit on a future Knowledge Sharing Event panel.

1. The next meeting date: **9 March 2022, 11-12pm via Zoom**. If you would like to Chair this meeting, please get in touch with Alice.