**Policy Group Meeting Summary**

**8 September 2021**

**11.00am**

**Attendees:**

Keith Park, MS Society, Chair

Carol Cochrane, Brainstrust

Catherine Patterson, Dochas Fund

Mary Ramsay, Essential Tremor Foundation

Colette McDiarmid, MND Scotland

Michelle Keenan, Edinburgh Headway

John Watson, Stroke Association

Jonathan Sher, QNIS

Leigh-Ann Connolly, Thistle Foundation

Stoo Brown, ME Action

David Mulligan, Funding Neuro

Beth Strachan, CBIT

Tanith Muller, Parkinson’s UK

Alice Struthers, NAoS

**Apologies:**

Sue Millman, Ataxia UK

Shirley Maxwell, Epilepsy Connections

Helen MacDonald, Lanarkshire Epilepsy – check

Colin Robertson, Dundee Headway

1. Chair’s welcome

After an introduction and welcome from Keith Park (Policy and Campaigns Manager, MS Society Scotland) apologies were made and everyone on the call introduced themselves and explained why they were interested in attending this meeting. Many mentions of the rising Covid-19 cases nationally, as well as an interest in hearing about the National Care Service Consultation.

1. Action points from previous meetings – follow up

The only outstanding action relates to NAoS inviting the Minister for Social Security to meet our members at an Autumn/Winter event. This invite has now been submitted and we are awaiting a response.

1. NHS Recovery Plan - thoughts and possible actions for NAoS

Keith gave a summary of the NHS Recovery Plan – it is 29 pages long and neurological services are not mentioned at all, whereas cancer, drug deaths and mental health are mentioned. There is also no mention of increasing workforce; the only workforce related commitment is in improving mental and physical wellbeing of existing health and social care staff. The only tenuous link to neurology is a commitment to increased funding in diagnostic procedures which will help speed up neurological diagnoses.

Members of the Policy Group agreed that the NAoS should flag our disappointment that neurology is not mentioned at all. The NAoS is happy to provide detailed plans on what recovery and rehabilitation looks like, but the Scottish Government needs to include people with neurological conditions explicitly as part of the Recovery Plan.

**Actions**

1. John Watson from the Stroke Association, and Keith Park from MS Society Scotland will work with Alice to draft a letter to the Cabinet Secretary for Health and Social Care with anecdotal evidence from their charities to make the case for including neurology in the NHS Recovery Plan.
2. National Care Service Framework – initial discussion of the consultation

The NAoS will be putting in a pan-neurological response to the NCS consultation, whose deadline has moved back to November 2nd. The consultation, which is 130 pages long, outlines what the NCS will look like. A lot of the content covers structural aspects of the NCS. The delivery component receives much less attention. The consultation is framed with sliding response questions, to measure how strongly people agree with various statements. Respondents are not expected to answer every single question, just those which have meaning for them.

Roughly half the charities attending the PG meeting confirmed they would also be putting in a response.

Jonathan Sher (QNIS) raised the point that the implementation of the NCS will take until 2025 and we understand there’s a necessary process before it is in place, but what is going to happen in the meantime? We are here individually and collectively to help take the work forward.

**Actions:**

1. NAoS to write to Kevin Stewart MSP, Minister for Social Care to make the point that we need action now, not in 5 years time and how can we help support more short-term strategizing and delivery of care to those who need it.
2. There will be major public policy conversations over the next five years about the National Care Service. Members of the NAoS want to create a sub policy group to take forward the NCS work. This is open to all NAoS organisations. If your organisation is interested in being part of this work, please get in touch with Alice with the name of the person within your organisation who is best placed to join this new subgroup.
3. Covid on the rise again in Scotland, how are charities feeling?

Parkinson’s – people living with Parkinson’s have become deconditioned through the pandemic and are now presenting at hospitals or at home visits with nurses in a much worse state than pre-pandemic. This is a worrying time which is exposing the fragility of our systems where high covid-19 cases are having a detrimental impact on the support people are getting.

MS Society- People with MS are reaching crisis point

ME Action -Covid-19 is seen as an acute illness but the real end point which impacts everyone is long covid (LCV). This can impact everyone, not just those with neurological conditions. A new CPG on LCV is meeting in Parliament today (8 Sept).

CBIT – The impact of the pandemic has been massive on education systems. Those with acute brain injury (ABI) already have limited focus, worse mental health and this impacts particularly on transitions.

Dochas Fund – rising cases of Covid-19 has impacted on the carer’s centre, with three forced closures due to staff isolating, in the 5 weeks since re-opening in August 2021.

QNIS- raised issue of Scotland’s Women’s Health Plan which isn’t in the Programme for Government and the non-communicable disease campaign which includes neurological conditions, the NAoS should be involved in these.

1. Horizon scanning

Neurological Framework – third round of funding – Tanith reported back from the recent NACNC meeting to say conversations are ongoing about the format of a third round of funding. We will continue to lobby Scottish Government for third sector organisations to be part of any third round of funding. We have had a number of anecdotes from members since April explaining that lack of feedback from round 2 was frustrating.

**Actions:**

1. Any members who would like to share their experiences with us of round two funding, please send a summary to us at info@scottishneurological.org.uk. If we collect enough information that can usefully be used to feedback to Scottish Government, we will anonymise everything and present it back to them, in order to improve the process going forwards.
2. A.O.B

None raised.

1. Next meeting date: 24 November 2021, 11-12pm via Zoom

NAoS Policy Groups are Chaired by a different member each time - if you would like to Chair the November meeting, please let Alice know.