**Policy Group Meeting Summary**

**24 November 2021, 11.00am**

**Attendees:**

Avril McLean, Action for ME, Chair

Catherine Paterson, Dochas Fund

Beth Strachan, Child Brain Injury Trust

Gillian Robinson, MS Therapy Centre, Lothian

Stoo Brown, ME Action

Thomas Mulvey, MS Society Scotland

Keith Park, MS Society Scotland

Carol Cochrane, Brainstrust

Tanith Muller, Parkinson’s UK

Stephanie Fraser, Cerebral Palsy Scotland

Alice Struthers, NAoS

**Apologies:**

Mary Ramsay, Scottish Tremor Society

1. Chair’s welcome

Following an introduction and welcome from Avril McLean (Projects and Participation Senior Practitioner), everyone at the meeting introduced themselves.

1. Action points from previous meetings – follow up

During the September 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. Keith Park (MS Society) and John Watson (Stroke Association) worked together with Alice to draft a letter to the Cabinet Secretary. This letter was shared with the NAoS Executive, who made some amendments to broaden the scope of examples given, and it was submitted on the 17th November. The letter raises our concerns about the NHS Recovery Plan published by the Scottish Government earlier this year, and asks if the Cabinet Secretary would meet with our member charities to discuss how NHS Scotland and the new National Care Service will provide the support that people with neurological conditions need.

There is one outstanding action, which is for NAoS to write to the Minister for Social Care, Kevin Stewart to ask for action now, rather than in five years’ time once the National Care Service is set up. Catherine Paterson (Dochas Fund) has agreed to work with Alice to draft the letter.

1. Assisted Dying consultation on draft proposal

This section formed the central part of the policy group meeting. Members were largely on the same page on this sensitive subject – united in wanting to give people a good death, but divided on whether legislation on assisted death is the correct way of doing this.

Stephanie Fraser (Cerebral Palsy Scotland) has recently spoken in the House of Lords on this same topic. Stephanie has concerns that the potential legislation is not well thought through, with insufficient safeguarding options, gaps in existing terminology and the risk of unintended consequences resulting from the current definition of terminal conditions. The definition of terminally ill in the Holyrood proposal is ‘unable to recover, irrespective of how much time they have left to live’. This includes plenty of people who are not dying. Stephanie pointed to the inconsistency across Scotland over current palliative care provision, which leads to some people having a good death whilst others suffer immeasurably.

The point was raised from research by Tanith Muller, Parkinson’s UK, that there’s a discrepancy between what someone with a condition thinks and wants for themselves, and what their carers think they want. Legislators may be in danger of second guessing what terminally ill people want. The statistic quoted in the recent [House of Lords debate](https://hansard.parliament.uk/lords/2021-10-22/debates/11143CAF-BC66-4C60-B782-38B5D9F42810/AssistedDyingBill(HL)) that 86% of disabled people are in favour of assisted dying was also raised and disputed.

There is an argument that the NAoS should be campaigning on access to palliative care, towards care enabling us to have a good death rather than taking a position on assisted dying. Irrespective of the way this legislation goes, we agreed we should be keeping the Scottish Government focussed on provision of quality and person-centre care.

If we were to put in a response to the consultation, the NAoS would want any legislation to build in robust safeguards to protect the lives of disabled people and those with long term conditions. The sense from members in attendance is that the current safeguards do not go far enough.

Action: Stephanie Fraser offered to draft a position on assisted dying for the NAoS executive to review.

1. NICE ME/CFS guidelines

Avril summarised the current position with the recently published NICE guidelines on ME/CFS. We are expecting the Good Practice Statement to be updated shortly as a result of the NICE guidelines, to remove the focus on Graded Exercise Therapy (GET) and to have more information around child safeguarding. SIGN is waiting to see if there is sufficient evidence to update the Scottish guidelines and will not move on this currently.

The question was raised as to whether even with the NICE guidelines, will it change the prescribing behaviour of primary care physicians and physiotherapists?

Gillian Robinson from MS Therapy Centre Lothian (physiotherapist) said it was concerning how little treatment there is for people with ME/CFS, with the typical treatment encouraging exercise which is now known to be damaging for some people with ME. There has been nothing from the Chartered Institute of Physiotherapists about the change in NICE guidelines, which means some people with ME will still be referred to do GET.

Stoo Brown (ME Action) said there’s a new hotline about to launch which people can use if they’ve been offered therapies in breach of the NICE guidelines. Exercise can still be recommended for people with ME, but only within the energy capacity that they personally have.

1. Patient Experience Survey

The patient experience survey which is currently in the field, will close 14 January 2022. The English Neurological Alliance will draft a UK-wide report on the experiences people are having, including access to services, preferences over appointment type (face to face vs virtual), the impacts of the neurological condition on life, waiting times to get a diagnosis, treatment, and care and support for the condition. The Neurological Alliance of Scotland will write up a Scotland-specific report which will be timed for release at the same time as the UK report. The discussion today centred around possibilities for members to use the quantitative data from the PES survey to tie in with recent reports they have done, or to combine it with qualitative data of their own.

The MS Society has recently released a report called [Neurology Now](https://www.mssociety.org.uk/get-involved/campaign-with-us/neurology-now) which members may also find insightful.

Action for ME are currently doing a poetry project, which will yield large amounts of qualitative data, which they can use.

1. Horizon scanning
2. Neurological Framework – SG about to launch round 3 with closing date 31 Jan 2022

Stephanie Fraser (Chair of the National Advisory Committee on Neurological Conditions) gave a brief update to say that round three will not be following the same open-bid format as the first two rounds of the Neurological Framework funding bids. Round 3 has a strong focus around [Commitment 9 of the Neurological Framework.](https://www.gov.scot/publications/neurological-care-support-scotland-framework-action-2020-2025/pages/6/)

Update: The Scottish Government opened Round 3 the day after the Policy Group meeting, on Thursday 25th November. NAoS is meeting the Clinical Priorities team Monday 29th November to see how we might be able to support some of their engagement activities with the third sector.

1. A.O.B

**Alice** mentioned the forthcoming Knowledge Sharing Event on 7th December, a member-only event presented by the Thistle Foundation about long covid. Registration is necessary to attend the online event, via: <https://www.eventbrite.co.uk/e/long-covid-facts-fiction-tickets-212548457157>

**Beth Strachan** (CBIT) mentioned the Acquired Brain Injury Private Members’ Bill which CBIT are involved with, via the UK Acquired Brain Injury Forum. The bill will have its second reading in the Commons on Friday 3 December.

The Bill is calling for a comprehensive strategy to be implemented to meet the needs of adults and children with an acquired brain injury. This strategy, to be published no later than April 2023, aims to improve the provision of services by local authorities, NHS, Department for Education, Ministry of Defence, Prison Service, Department for Work and Pensions and the Department for Digital, Culture, Media and Sport. You can  watch a short introductory film about the Bill [**here.**](https://458rl1jp.r.us-east-1.awstrack.me/L0/https:%2F%2Fyoutu.be%2F2Vj_2m-uwxs/1/0100017cb7779895-10cac27d-6e4a-4280-9014-03edbc96b1aa-000000/8y9v9ZNQ5nR02VB2uR3-9cuA8GY=241)

1. Next meeting date: 12 January 2022, 11-12pm via Zoom

We would like to support one of our smaller members to Chair the next policy group meeting in January – if you volunteer at or work for a small charity, let Alice know if you’d like to be involved.