**Policy Group Meeting Agenda**

**6 November 2024**

Attendees:

Kripen Dhrona, Chair, BPF

Alison Philipps, SCCMI

Mark Jackson, PSPA

Claire Stevens, NAoS trustee

Catherine Martin, SHA

David Mulligan, Funding Neuro

Claire Winchester, MS Trust

Ewan Dale, ME Association

Gillian Mathewson, PANS PANDAS

Iain McWhirter, Revive MS Support

Keith Park, MS Society

Liam MacLua-Hodgson, The Brain Tumour Charity

Avril McLean, Action for ME

Pamela Binny, ME Action

Apologies:

Rachel Edwards, Epilepsy Connections

Vicki Cahill, Alzheimer Scotland

Mary Ramsay, Scottish Tremor Society

Steve Portelly, FND Hope

AGENDA ITEMS

1. Chair’s welcome – Kripen Dhrona, CEO British Polio Fellowship

Kripen Dhrona welcomed everyone to the meeting and gave the apologies. Kripen gave a short introduction to British Polio Fellowship. Their primary aim is to support polio survivors to lead full, integrated lives. Kripen mentioned the new Post-Polio clinical pathway which was developed through 2023 and which the Fellowship is promoting now.

1. Action points from previous meetings – Alice Struthers, NAoS

* Outstanding actions include members of the policy group to share our Mental Health report with any Cross-Party Groups that you are part of. If you haven’t seen a copy of the report, [you can access it here.](https://www.scottishneurological.org.uk/files/mental-health-report-final-(16)-(3).pdf)

**No other outstanding actions**

1. Mental health subgroup update – Alison Philipps, Chair of subgroup

Alison thanked everyone for the opportunity to represent the subgroup at this meeting and thanked outgoing Chair, Keith Park for all the work he had done to date. Alison provided a short introduction to her role, which involves working in partnership with the NHS and other organisations to develop early intervention services that foster physical and mental wellbeing services for children with confirmed or suspected neurological conditions.

The Mental Health subgroup has been through a membership renewal, asking members to opt back in if they wanted to continue being part of the group going forward. The group subsequently dropped in size slightly and would welcome others from the policy group who feel they have capacity to contribute to the work of the subgroup.

The subgroup has spent time resolving some operational issues to keep things moving. Meeting dates and times for the next 12 months have been set and published. We have explored SharePoint to allow us to share documents between meetings. We have revised the Terms of Reference and tightened up our Engagement Plan. We have written to Cllr Kelly, the COSLA health and social care rep, inviting him to a meeting to discuss the recommendations of our report. We have written to the Mental Health CPG with the report offering to meet to discuss the recommendations with them. The focus is now on turning the report’s recommendations into actions.

**Action: Please contact alison@craighalbert.org.uk if you are interested in joining the subgroup**. T**he next meeting will be on 12 December, 9 –10am.**

1. Manifesto subgroup update – Mark Jackson, Chair of subgroup

Following a short introduction, Mark explained that the purpose of this subgroup is to have a co-ordinated approach to the 2026 Holyrood election, to be a collective voice for campaigning for neurological services and for the ongoing sustainability of the neurological third sector. It will be an evidence-based manifesto, drawing on data from the 2024 My Neuro Survey. We’d like to use it as a tool for lobbying parties ahead of the election, and to inform their own manifesto formation, as well as using it as a campaigning tool into the next Scottish parliamentary term.

The group has been established with reps covering all the categories amongst our membership, from acquired conditions, children and young people, life-long, life limiting, fluctuating, neurodegenerative, movement disorders and wheelchair users. The idea is to cover as many bases as possible to inform our views.

We have had two meetings so far, which has brought up some broad themes that the manifesto will cover.

* Principles of what good quality care and support should look like
* Funding and the need for a long-term funding settlement and the sustainability of the sector
* The importance of understanding prevalence to accurately plan and support services including more efficient investment into research
* Workforce – recruitment and retention gaps, the need for a multi-disciplinary approach
* Wider determinants of health – from access to education for young people to disability benefits and carer health

The next phase is to review the data from the My Neuro Survey when it becomes available at the start of 2025 and understand what it is telling us about patient experience. We also need to ensure that the manifesto is as reflective as possible of the views of NAoS members more broadly. We plan to pull together a matrix of issues from across membership to identify commonalities and divergences of views.

We are expecting to have a manifesto document ready for members to use from September 2025 ahead of the party conference season.

If there is a snap election in the meantime, this group would pull together a shorter overview of the key issues to use as a campaigning tool, focussing on one or two core key messages which would most likely include funding and sustainability. We would carry on doing the other work for a full manifesto for 2026 as well.

**Action: Mark to reach out to policy group to gather information for the ‘matrix’.**

**The group meets every 6 weeks, scheduled ahead of the policy group meetings.**

**Dates remain to be set. The group is open to new joiners if anyone is interested – please email** [**alice@scottishneurological.org.uk**](mailto:alice@scottishneurological.org.uk) **and** [**mark.jackson@pspassociation.org.uk**](mailto:mark.jackson@pspassociation.org.uk)

1. Update on Ministerial meeting, 10 October, re sustainability of third sector social support – Alice Struthers

A short update was given on the meeting held at Scottish Parliament with the Minister for Public Health and Women’s health, Jenni Minto MSP. This was a meeting held with NAoS Chair, Vice Chair and Programme Director along with the Minister and two of her officials. The point of the meeting was to discuss the crisis in sustainability of third sector social support. The result of the meeting was an agreement from the Minister that we should put third sector together with NHS Commissioners for a discussion about how to maximise the services that are available. We also need to flag that there is a danger that we end up with more signposting to third sector organisations, without any funding which will increase the burden on our services.

**Action: NAoS is meeting Scottish Government next week (w/c/ 11 Nov) and will review how we take it forward there.**

1. Horizon Scanning (consultation responses, Parliamentary activity of interest etc)
   1. [Palliative Care Scotland bill (SG / Citizen Space)](https://consult.gov.scot/healthcare-quality-and-improvement/palliative-care-matters-for-all/)

NAoS will be drafting a response. Call for policy group members to support the drafting and review. Several policy group members put themselves forward. **Action: Alice to send an initial draft to this subgroup ahead of Christmas. The deadline to the consultation is 10 January 2025.**

* 1. Budget failure and subsequent snap Holyrood Election

Short discussion about [NCVO](https://www.ncvo.org.uk/news-and-insights/news-index/open-letter-chancellor-national-insurance/) and [SCVO](https://scvo.scot/p/94630/2024/10/31/scvo-respond-to-uk-government-autumn-budget-2024) template letter/s about charities, particularly those providing essential public services being exempt from NI increases. We are expecting the impact between NI increases and wage increases to have a significant impact at c.3% per charity. We are likely to see services being reduced, posts not being filled or posts being cut. It’s too early to know whether charities will have to reduce their workforce as a direct result. In addition, charities are very concerned (if not, more concerned) about statutory service cuts as well – including IJB cuts. These cuts could result in as much as a 40% of loss in funding for charities. There’s a possible role for NAoS in advocating for the health part of the barnet consequential to Scotland to be ringfenced for health.

**No action at this time.**

* 1. NCS, Green Party withdrawal of support and Cllr Paul Kelly (Health and Social Care Spokesman for COSLA) coming to our 20 Nov Members’ Meeting – questions to ask him

Discussion over opportunity to ask questions in advance which was was taken offline.

**Action: Please send any questions you would like to ask Cllr Kelly to Alice by 11 November**

* 1. [Interim Adult Disability Payment report](https://www.gov.scot/binaries/content/documents/govscot/publications/independent-report/2024/11/interim-report-independent-review-adult-disability-payment/documents/interim-report-independent-review-adult-disability-payment/interim-report-independent-review-adult-disability-payment/govscot%3Adocument/interim-report-independent-review-adult-disability-payment.pdf) due out start of November and possible follow up meeting with Edel Harris

**Action: Can policy group members have a look through the interim report and share any thoughts with Alice ahead of the next policy group meeting on 19 Feb when we will be welcoming Edel Harris to our meeting for the chance to discuss the report.**

1. A.O.B

Nothing raised.

1. Next meeting date: Wednesday 19 February, 11.00 – 12.30

Notice of change of date for the next policy group meeting which is now on the 19th Feb, from 11- 12.30, slightly extended because we will be welcoming Edel Harris, Chair of the ADP review, to this meeting.