# Trustee Meeting Minutes

## 20 January 2025, 10.30 - 12.30

#### Attendance:

Jenn Hall, Chair

Iain McWhirter, Treasurer

Nicky Cowsill, Neuro Hebrides

Avril McLean, Action for ME

Steve Portelly, FND Hope UK

Donald MacPhee

James Jopling, Parkinson’s UK

Claire Stevens

Ewan Dale, ME Association

Alice Struthers, NAoS

Hester Lee, NAoS

#### Apologies:

Keith Park, MS Society

Roisin Eadie, Scottish Huntington’s Association

David Mulligan, Funding Neuro

## Chair’s welcome

Declaration of any conflicts of interest: No declaration of conflicts.

**NACNC update:**

No NACNC meeting since last trustee meeting.

Discussion regarding continuation of the NACNC. Framework coming to an end and the Chair of the NACNC is stepping down- sense that the NACNC and the framework may be getting merged into long term conditions. No concrete communication about this from Scottish Government, Alice to meet with Richard Brewster to discuss.

Jenn noted there’s been no communication from NACNC or Stephanie (Chair of NACNC) about stepping down, nor has it been said that the NACNC will end, so further clarification is needed to be able to update members.

**Update on the Long Term Conditions strategy meeting:**

Scottish Government held a Long Term Conditions Strategy meeting in November and presented a vague proposal to bring all conditions into long term conditions strategy. Concerns were raised about the direction of this from major charities. Meeting didn’t provide an explanation as to why this is happening.

The worry about neurological framework being moved to long term conditions was raised by NAoS in the NACNC.

Suggestion that it would be worth engaging with Tejesh Mistry from VHS as they could offer solidarity/a voice - e.g. guest blog on their website and in their enews etc.

**Actions**:

* Alice to contact to Health and Social Care Alliance and Tejesh Mistry to understand their positions on Long Term Conditions Strategy and draft NAoS position on this proposed change
* James Jopling to contact British Heart Foundation to understand their position on the LTC strategy.

1. Actions and approval of minutes from the November trustee meeting

Actions update from last meeting:

* Jenn gave update that digital switch over is now happening in 2026, this gives NAoS more time to understand what we want to do in terms of raising awareness and how we want to influence the Government on how to best support people with this change.
* With regard to having a procedure if members are concerned NAoS is applying for similar trusts, Iain does not feel like this is a concern NAoS needs to have.
* Discussion regarding how best to field SMC and NICE enquires. The approval of drugs can be country specific depending on how the pharma companies have negotiated with NHS. Suggestion to enquire with SCVO and VHS to see how they navigate call outs from SMC as NAoS could help smaller charities engage with these requests who may not have capacity.

**Minutes approved:** Proposed, Nicky Cowsill. Seconded, Ewan Dale

**Actions:**

* Ongoing actions – Alice to draft an average spend for NAoS per month to inform the reserves policy and send to trustees
* Alice to put a call out to SCVO policy network and VHS to see how they navigate SMC call outs to help smaller charities engage with these requests.
* Have a separate action log which keeps actions going until they are closed

1. Financial update (Iain)

Update from end of quarter 3 (December 31):

Income and expenditure – There is a variance as a result of a few membership fees which have not come in. Everything is fairly phased, no unexpected expenditure planned for rest of financial year, should be on track for budget.

Projected reserves of 8 months at the end of March which takes us to end of November 2025. Still uncertainty regarding funding meaning we have a material uncertainty for ongoing funding after November 2025 and this should be reflected in the risk register. May consider whether we look to reduce our anticipated expenditure for the next financial year to stretch out our reserves and expenditure.

Question regarding National Insurance increase and whether this will affect the budget. Alice and Hester are contractors, so the NI employers increase does not impact NAoS. NAoS has checked that we are in line with the IR35 and we are considered contractors.

Question as to whether we have any upcoming costs that are unnecessary. Our next projected major costs will be for the PES publication and promotion but this will fall into the next financial year. Suggestion that we should keep money for unspecified costs e.g outcomes we might wish to pursue after My Neuro Survey.

Alice to draft budget for trustees approval at meeting in March.

**Bank account update:**

Concerns from trustees about RBS bank account format however this is a minimal to no risk for NAoS as this situation does not apply to us. RBS offer free accounting software so seem like best option. No objections from trustees with this course of action, Iain will progress with this route.

Question about where conversation ended with Scottish Government after we last received funding. Alice explained that there was no conversation – it seems they will not be funding us but they give the general advice that we’re welcome to apply to any pots they have if our objectives meet theirs. Trustee support for this suggestion- a stage in our move to be more sustainably funded could be to carve our work into silos that fit Scottish Government departments.

Discussion as to whether NAoS wants our relationship with Scottish Government to continue if funding ceases. Helpful for us to have a route in to Scottish Government. The challenge of the Long Term Condition strategy may also mean we want to have a way to voice our concerns and be part of conversations. We can continue meeting but under our own priorities. Need to consider our role in Neurology Network carefully- how to be a constructive and good partner.

**Actions:**

* Alice to update risk register to reflect the uncertainty of funding
* Alice to draft budget for March trustee meeting
* Iain to progress with RBS bank account
* NAoS to ask Scottish Government how we are to continue attending meetings unfunded

## Fundraising update (Alice)

Trustee fundraising group have had sight of our PES project outline. This has been sent to three charitable trusts. With regard to sustainability, it might be that NAoS can do 3 applications a month. We have drafted an application for a website redesign but are seeking larger quotes from developers for more ambitious redesign.

Three string approach for financial sustainability:

* Charitable trusts
* Pharma project funding
* Pharma industry group – mirrors what English Alliance do. It’s a bigger ask as they have meetings throughout the year looking across what’s happening in NICE/SMC context, policy and laws. Georgina also has one to one meetings with the pharma companies, and invites certain trustees who are relevant to attend. It took Georgina 1/5th of her time to get it set up (a day a week) so this would be 1/3rd of Alice’s time.

Having advanced notice that a drug may be coming up to review for SMC is helpful for charity members to go out to patient groups to ask whether they have been involved in clinical trials/ engagement. A relationship with pharma companies could be beneficial for NAoS as an intermediary- we’re in a better position to facilitate this relationship in a safer way than individual charities.

Noted that NAoS is small and cannot offer the same as the English NA. Our offer would be as a conduit to organisations that pharma may not know about. Agreement our value is our knowledge and network so if we can harness this than that would be beneficial.

NAoS can still seek funding from Pharma in the shorter term through their patient advocacy pots and build the membership offer into a longer term strategy. Pharma companies are also interested in funding things that are not drug related.

Question about scale of operation of pharma in Scotland. Doesn’t matter about operation location, rather the public engagement team reach out to stakeholder groups. Avril McLean can provide the contact for someone who works with pharma reps in Scotland.

Hester in process of registering with HMRC to enable NAoS to create Just Giving profile which would mean others could fundraise in the future.

**Actions:**

* Alice to develop pharma plan
* Avril to provide contact who works with Pharma representatives in Scotland

## Q42024 (Alice)

Alice gave overview of quarter 4 workplan priorities- paper circulated to trustees prior to the meeting:

* PES – data delayed, therefore can’t reach out to health boards yet to do the data socialisation. Scottish Government colleagues will help us reach out to those who were involved in the self evaluations once we’ve received the data.
* Brain Awareness Week – all on track, research scientists involved in content production and open letter in draft.
* Policy Group-
  + Alice submitted 10 PQs through Jackie Baillie
  + Palliative care consultation submitted
  + Mental Health subgroup very active – meeting Scottish Government Mental Health team after next Members Meeting.
  + Manifesto subgroup- worried about the progress of this group as the chair was unresponsive for a couple of months.
  + ADP – Edel Harris is due to be coming to Policy Group meeting on 19th Feb.
* UK Neuro Forum – happening on 10th March. Looking for someone who would go to Leeds to be at the launch. NAoS will be heavily involved in agenda and Georgina Carr (NA England) suggested an all member meeting to draft agenda priorities.
* Membership- NAoS to create a membership survey to try and understand how membership is feeling prior to rebilling in April.

Query regarding other alliance’s involvement in Brain Awareness Week- agreement across alliances on main messaging and theme. Workload has been a little unevenly distributed, noted that Wales and Northern Ireland don’t have the same capacity as Scotland or England to contribute time.

## Risk Register update (Alice)

Overview of risk register: all risks have gone down however the funding risk will now go back up unless we receive funding before next trustee meeting. No new risks and all changes have been decreased (listed on the tab ‘changes to risk register’).

Actions:

* Hester to send risk register as a excel sheet rather than a PDF

## Membership update (Hester)

We’ve informed Dochas Carers Centre and the Thistle Foundation that we were ceasing their membership as we’ve not received their 2024/25 membership fee nor heard from them. Nerve Tumours UK have joined our membership. We’ve invited the FASD Hub to join NAoS and Hester has been in contact with Rare Dementia Support (ongoing conversation) regarding membership.

Main contact updates at Compass and CBIT (see membership review paper).

Hester gave overview of member pipeline- looking both at charities who are OSCR registered and those who are only registered with the Charity Commission but operate in Scotland.

Steve noted FND Dimensions were at event in Parliament and were looking to expand in Scotland- may be potential good contact. Ewan Dale suggested Long Covid Scotland.

**Actions:**

* Alice and Steve to discuss CMT support groups
* Hester to make contact with Long Covid Scotland, CMT UK and FND Dimensions

## Overview of Member’s Meeting agenda- item removed due to lack of time.

Members Meeting talking topic- whether members have seen impact on recruitment and retention of NHS staff after funding announcements.

NAoS has asked for an update on the spend of the £4.5 million in the parliamentary questions. Revive MS have a similar question lodged with civil servants following the First Minister’s visit to Revive in December, Iain to share with NAoS once received.

**Action**:

* Iain to share response from civil servants once received regarding the questions Revive MS asked following First Minister visit

## AOB

Update on the Parliamentary reception in Houses of Parliament from Steve and Donald. General feedback that the event was very valuable. Agreement from Donald, Steve and MPs that NAoS should have a similar event in Holyrood for MSPs and that it would be very useful to help raise awareness.

Question from Steve regarding if English Neurological Alliance, doctors and psychiatrists have seen the Mental Health Report. Alice sent the report to English NA (and other UK neuro alliances) and requested that the first topic for the Neuro Forum should be Mental Health. Not aware if any doctors or psychiatrists have seen report, NAoS does not have strong connections with these circles.

## Freelancer Vs employee model discussion with trustees only

**The next Exec meeting will be held on Monday 31 March, 10.30 - 12.30pm**

## Action log:

* Alice to contact to Health and Social Care Alliance and Tejesh Mistry to understand their positions on Long Term Conditions Strategy and draft NAoS position. James Jopling to contact British Heart Foundation to understand their position.
* Ongoing action – Alice to draft an average spend for NAoS per month to inform the reserves policy and send to trustees
* Alice to put a call out to SCVO policy network and VHS to see how they navigate SMC call outs to help smaller charities engage with these requests.
* Hester to create separate action log sheet which keeps actions going until they are closed
* Alice to update risk register to reflect the uncertainty of funding
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* Alice to continue development of pharma plan
* Avril to provide contact for person who works with Pharma representatives in Scotland
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