# Trustee Meeting Minutes

## 10.30am - 12.30pm, 31 March 2025

## Attendance

Jenn Hall, Chair

Keith Park, Vice Chair

Nicky Cowsill, Neuro Hebrides

Donald MacPhee

Roisin Eadie

Avril McClean

Ewan Dale

Alice Struthers, NAoS

Hester Lee, NAoS

## Apologies

Claire Stevens

Iain McWhirter

Steve Portelly

James Jopling

David Mulligan

## Chair’s welcome

Alice Struthers noted she is in conversation with a charity about becoming a trustee but this should not provide any conflict. No declaration of any conflicts of interest from NAoS trustees.

Jenn gave update on National Advisory Committee on Neurological Conditions (NACNC):

* A few members of the NACNC are stepping down including chair Stephanie Fraser. NACNC will continue in its current format, Jenni Preston will be chair.
* 74% of funded projects through the Framework demonstrated that funding was crucial to them continuing with only 26% being scalable and self sustainable.
* The Service Improvement Forum (SIF) is being discontinued and Susan Walker stepping down as chair. The improvement plans and updates from this work will now be fed directly to the NACNC.
* Comment from Alice that NAoS need to make sure we hold those responsible for delivering the outstanding work to account.

Long Term Conditions Strategy update form the NACNC and discussion:

* NACNC was attended by Louise Scott from Long Term Conditions (LTC) strategy unit to present on LTC strategy plans. Consultation will go live soon and LTC framework will be published in autumn.
* The LTC strategy unit intend to use a prioritisation matrix to crosscut areas and identify key priority targets where they will focus work. Within this there will be generic issues and some condition specific, however, this could mean neurology wide or it could mean condition specific. No detail was given and it is not clear how they will be capturing the huge amount of long term conditions within this matrix. Comments made that the “prioritisation” as a method does not benefit conditions with smaller populations and this concern is echoed by members of the NACNC. Scottish Government stress it won’t be done on prevalence but it’s hard to see how else it will be prioritised.
* Keith, Jenn and Alice have meeting with Minister Jenni Minto in May to talk about the LTC open letter NAoS sent to Scottish Government.

## 2. Actions and approval of minutes from the January trustee meeting

Actions from last trustee meeting reviewed. Please see new action log for up to date record of this.

Update on outstanding actions:

* Alice to write blog about LTC strategy for Voluntary Health Scotland to publish after meeting with Minister in May
* Alice to put a call out to SCVO Policy Network and VHS to see how they navigate Scottish Medicine Consortium call outs to help smaller charities engage with these requests- Alice didn’t think this was relevant for the Policy Network so did not post on this network. Not in the remit for NAoS to do these submissions, however we may be able to help connect smaller organisations link up with bigger members.
* NAoS to ask Scottish Government how we are to continue attending meetings unfunded- the decision was made that whether or not we’re funded we want the relationship to continue and as such this was not raised in the March meeting. However, Jenn and Keith will raise future funding in meeting in April regarding NAoS’ progress.
* Alice to continue developing pharma plan- we plan to action this with new fundraiser.
* Hester to contact FND Dimensions about membership- Alice noted that we want to focus our attention on growing fee paying members, therefore this action is not a priority and can be removed from the list.

Nicky Cowsill proposed the minutes and Donald MacPhee seconded.

**Actions**:

* Alice to write blog about LTC strategy for Voluntary Health Scotland to publish after meeting with Minister in May.
* Iain to give update on bank account progress at next meeting.

## 3. Financial update

Alice gave profit and loss update on behalf of Iain:

* Overall 2 % down from projected budget as NAoS received less membership fees and a lower accumulation of bank interest as a result of late payment of grant from Scottish Government.
* Without extra funding, NAoS has 8 months expenditure from now.
* OSCR request for our accounts received; accounts will be prepared and independently examined before NAoS’ AGM on Weds 24 September. Alzheimer Scotland could host again.

Alice presented the two budgets for 2025-6: one is based on no additional funding received and one is based on successfully getting the Scottish Government grant and additional funds from trusts, grants and pharma.

Budget 1: inflationary increases on all expenditure apart from freelancer fees and subscription fees. Training and recruitment costs reduced. Estimates 100% of retention of members. This budget takes us to November.

Budget 2: estimates trusts and grants income of £68k (Scottish Government grant and charitable trusts/ pharma). Membership income estimate unchanged. Inflationary increase for freelances fees (3% for Hester and 6% for Alice as her fee has not changed since 2023) and added cost of freelance fundraiser 1 day a week. Estimate is that investment in a fundraiser should be a 3 to 1 return. Staff training and recruitment are still reduced; website redevelopment cost factored in.

NAoS could add in the fundraiser position to budget 1 but we would run out of funds by the AGM. This may enable NAoS to have some income coming in if no funds are received from Scottish Government.

Question regarding whether hiring a fundraiser will reduce the Scottish Government grant. It should not affect our chances of getting the grant as Scottish Government wants us to be sustainable by 2026. Therefore, it may be beneficial to show we are being proactive in hiring a fundraiser. There may also be a shortfall in grant money, so hugely important to diversify into pharma as soon as possible to mitigate our reliance on Scottish Government.

Discussion around wage increases, the difference in cost would be just under £3,000.

Trustees supportive of hiring fundraiser and including wage increases in both budgets.

Suggestion regarding purpose of website and cost effectiveness. Scottish Huntington’s redeveloped website recently as cost much lower than NAoS’ projection. Also noted that with recruitment at SHA they are having to put each post out twice, so important to keep budget for recruitment.

**Actions:**

* Alice to make third budget with no income received, added cost of fundraiser, freelance fee increases and further tweaks e.g change for training and recruitment. Alice will send round the third budget to trustees.
* NAoS to hire a fundraiser
* Roisin to send NAoS website developers Scottish Huntington’s Association used
* Jenn to confirm whether NAoS can host AGM at Alzheimer Scotland National Office in Edinburgh

## 4. Workplan Q12025

Alice gave overview of My Neuro Survey which is currently NAoS’ main project. Alice has drafted data presentation which she is delivering to Scottish Government and members.

NAoS received a robust data sample, however the child survey (child answering on behalf of themselves) was a very low response rate at 11 responses. This trend is reflected across the UK and the other alliances agree going forward we will not do a Children and Young Person survey.

Between April and May Alice will be focusing on data socialisation with Health Boards and writing the report (to be published in June). The report may be launched at the MS Cross Party Group at end of June but this would mean the report would have to be finalised by mid May. Having a media engagement plan is very important- last time NAoS used Quantum who were very good and offered a charity rate.

Policy Group – Alice to meet with local Authorities to talk about mental health report and impact on Children and Young People. Long Term Conditions meeting with Minister Jenni Minto MSP scheduled for May and Laim McArthur MSP will attend NAoS’ next policy group meeting to discuss Assisted Dying. The manifesto subgroup is behind on their work- need to regain policy members who are engaged to help progress this work.

NAoS intends to run a short survey at our Members Meeting on Wednesday to understand the value of meetings with the aim of increasing membership attendance. Alice noted we also need to understand how to engage bigger members who have more resources to get involved.

KPIs have been cut down in line of our strategic aims. Key highlights include:

* Intent to host hustings for elections
* PES report and debate – Alexander Barnett is happy to sponsor another debate in the autumn
* Manifesto created by September
* 100% external event reporting – need system for Alice to share external event reports to members
* Meaningful collaboration with health boards through the network
* Influencing government and local authorities by assuring 100% attendance at critical meetings
* Continuing to engage with Brain Awareness Week
* Evaluate the success of the framework and write a report – Alice noted this will be pushed to 2026/27. NAoS can use the time now to gather data and benchmark on Scottish Government report which is due to be published.
* Sustainability – could be achieved through recruiting freelancer fundraiser.

## 5. Risk Register update

Alice gave update of risk register – a few risk increases:

* Lack of financial controls- NAoS does not have a bank account and relies on Engage Renfrewshire for all payment of invoices and bank controls.
* Lack of reporting and internal comms – improvements to be made in methods of debriefing on external groups and meetings.
* Failure to open bank account.
* NAoS not able to generate sufficient income.

**Action**: Jenn to give trustees an update on how the meeting with Scottish Government goes.

## 6. Membership update

Hester gave membership update, please see paper.

Question from Ewan regarding developing better contacts within research to have something to offer research focused charities. Avril noted Action for ME try to keep a research register but it’s very hard to keep on top of so it may not be cost effective for NAoS.

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## 7. A quick look over the Member’s Meeting agenda

Alice gave overview of agenda. NACNC and UK Neuro Forum update, Brain Awareness Week presentation and My Neuro Survey presentation on data are key areas for the meeting.

8. UK Neuro Forum launch feedback and next steps

Keith was unable to give update as his power dropped and was not able to rejoin the meeting. Keith to give update at members’ meeting on UK Neuro Forum launch.

## 9. BAW highlights

Hester gave overview of Brain Awareness Week and outcomes. [See presentation for members here.](https://www.scottishneurological.org.uk/file-download/68/baw-2025-member-presentation.pptx)

Very collaborative campaign- huge thanks to the working groups for their time and commitment, particularly Nicky and Steve. Content wise- NAoS had 22 videos from volunteers across research, lived experience and members. Saw a significant increase in reach and views across our platforms, including launching our new TikTok which gained good traction. 22 members took part (up from 18 last year) and the campaign was also picked up by organisations outside our membership such Neuroprogressive and Dementia Network, the Brain Health Arc, ANCR journal and other groups across the UK. Received confirmation of receipt of open letter from Secretary of State, awaiting further response. Overall the campaign performed really well.

## 10. AOB

Impact report 2024/5 presented to trustees - [see here.](https://www.scottishneurological.org.uk/file-download/64/20245-impact-report-(5).pdf)

Alice asked whether trustees are happy with the impact report as our main method of reporting. General comments agree that short, simple and visual is beneficial for demonstrating impact.

Changes to charity law – trustees to read paper.

Networking session update / feedback from attendees- trustees to read paper on networking session update.

**The next Exec meeting will be held on Monday 23 June, 10.30 - 12.30pm**

## Action log

* Alice to write blog about Long Term Conditions strategy for Voluntary Health Scotland to publish on their website after NAoS has met with the Minister in May.
* Iain to give update on bank account at next meeting.
* Alice to make third budget for trustees: no income received, added cost of fundraiser, freelancer fee increases and further tweaks.
* NAoS to hire a fundraiser after budget has been approved.
* Roisin to send NAoS the website developers used by the Scottish Huntington’s Association.
* Jenn to confirm whether NAoS can host next AGM at Alzheimer Scotland National Office in Edinburgh on 24 September.
* Jenn to give trustees an update on how the meeting with Scottish Government goes.
* Trustees to read papers on charity law changes and the networking session update.