

Members’ Meeting Summary

**Online via Zoom**

**16 June 2022**

**10.30am – 12.30pm**

**Attendees: Apologies:**

Tanith Muller, NAoS Chair, Parkinson’s UK Stoo Brown, ME Action

Rona Johnson, NAoS Vice Chair, Epilepsy Scotland Alistair Haw. SHA

Leigh-Ann Little, The Oxygen Works Jonathan Sher, QNIS

Carol Cochrane, Brainstrust Dawn Golder, FND Hope

Caroline Morrice, GAIN

Colette McDiarmid, MND Scotland

Colin Robertson, Headway Dundee & Angus

George Allan, SPPN

Sue Millman, Ataxia UK

Ewan Dale, ME Association

Beth Strachan, CBIT

William Oviatt, Thistle Foundation

Iain McWhirter, Revive MS Support

Karen McCurry, MS Therapy Centre, Mid Argyll

David Milligan, Funding Neuro

Keith Park, MS Society

Nancy Campbell, MS Therapy Centre Lothian/Compass

Avril McClean, Action for ME

Alice Struthers, NAoS

Phil Robson, Lanarkshire Epilepsy

Claire Winchester, MS Trust

Helen Bulbeck, Brainstrust

Rebecca Packwood, PSPA

Marc Smith, Brain and Spine Foundation

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| 1 | Chair’s welcome and Scottish Government update | A warm welcome was given to Iain McWhirter (MS Revive) who has recently joined the NAoS Executive.Rona Johnson is leaving Epilepsy Scotland and will therefore leave her position as Vice Chair of NAoS. Rona will remain in post until she leaves at the end of August. We would like to thank Rona for all her hard work over the past couple of years. It has been hard to keep NAoS going over lockdown and covid and bringing the sector together at a time that has been difficult for everyone. Rona has been fabulous at making sure things happen. We wish her all the very best in her new role in the Scottish Government.We are delighted to welcome Morna Simpkins from the MS Society as our new Vice Chair.In terms of our executive, our AGM in September will be another opportunity for members to stand on our Executive. Please can those interested speak to Tanith or Alice and register a note of interest by the 1st September. There will be formal elections at the AGM in September. |
| 2 | NACNC update | One of the things we were keen for the Scottish Government to do is to improve data collection for neuro conditions as no-one knows how many people there are living with neuro conditions and what their needs are. We are really pleased that phase 1 which was to interrogate the Primary Care database in Scotland about common neurological conditions has been completed. We are going to see if we can get someone from the SG to speak at our AGM about what they’ve found out. Action: Alice to find a statistician speaker for AGM Secondly, there are moves afoot in SG around specialist nurses. Rona, Alice and I were involved with a meeting with the CNO office regarding specialist nurses. We raised a specific issue in NHS WI where specialist nurses are being removed and replaced by a general neurological Clinical Nurse Specialists (CNS). We were disappointed from the response from colleagues in that group who didn’t give as fulsome a defence of the CNS model as we would have liked. It brought to the core a piece of work that government has been working on that NAoS isn’t involved with, which is a review of clinical specialist nurse competencies which is being led by Judith Newton, an MND CNS and who is reporting into a different part of SG. That process is really lacking transparency so we want to put on the record that we have a few concerns about that and we’re trying to find out more about what’s going on.Those who were at the joint MS/Epilepsy CPG last week, will have heard the Minister’s answer about specialist nursing in the Western Isles (NHS WI), which from our point of view, is not the answer we are looking for, and we were not convinced the Minister is fully behind what she was saying. Her answers were disappointing.Sue Millman (Ataxia UK): What is the SG proposing to do with specialist nurses?Tanith: The NHS WI model is that they previously had specialist nurses for MS, epilepsy and Parkinsons. The MS and Epilepsy nurses have both left their posts and rather than replace them, they’re looking at having two nurse specialists covering ALL neurological conditions in their case loads across the whole of the Western Isles. It’s a very remote rural community, people are spread out over a huge area. There is room for general neurological nursing but that’s better provided in centres where there is also expertise on tap on site. The issue here is that you are still a flight away from a consultant who can tell you what’s happening. NHS WI is saying two nurses are more sustainable than three, and that it is less individually reliant. We dispute this as if something happens to either of those two posts there’s a problem. They are also looking at having a growing caseload in all 3 conditions that had specialist nurses, where one condition has a live patient safety alerts over sodium valproate, and MS disease modifying drugs which need careful monitoring, and Parkinson’s which also has complicated medication. All three of these conditions are medically driven and need the expertise to manage them.There was no consultation with the local people with neurological conditions. Neuro Hebrides (a local group) were told they were informed what would happen rather than asked about it. MS Society and Parkinson’s UK held a meeting with Neuro Hebrides who were very agitated about it.The wider problem is that the CNO directorate seem to be misinterpreting the pyramid in the Neuro Framework. This is where people have self-management at the bottom and specialist nursing at the top. The whole point of that pyramid is that most people with neurological conditions will be on all three levels at the same time. It isn’t the case that only the top 5% need specialist nursing care. NHS WI is saying this model has been used very successfully in NHS Shetland. The NHS Shetland model is reasonably effective, however the difference is that when it was being set up, they spoke at length to Parkinson’s UK and other conditions that rely on medication. There is also very good support from NHS Grampian. We don’t know if there is similar support for NHS WI from NHS Greater Glasgow & Clyde (NHS GGC).Keith Park (MS Society): the specialist nursing provision in NHS Shetland was less than the capacity in NH WI. There was more of a handover process too. Sue Millman: There ought to be a read-across to the Scottish Rare Disease framework which might contradict the actions taken in NHS WI. Secondly, they should develop a hub-and-spoke arrangement where the specialist nurses can relate to experts about those conditions. They are talking about a protocol for remote appointments on the rare disease framework, where they should and shouldn’t be used. For instance, if they could have a nurse in the appointment with the person, with the expert at the end of the video call, it could improve the service a bit.Tanith: There is an issue separately arising over how virtual consultations should be used in Scotland. One of our members flagged a serious breach of that with a vulnerable patient. Rona Johnson (Epilepsy Scotland): We’re supporting an older person with epilepsy in NHS GGC. They don’t get the support they need over the phone so they requested a face to face appointment but were told this doesn’t happen anymore for epilepsy. She was told that a face-to-face request would have to go to management. The person was left very distressed and went on to have a serious seizure. This goes against everything NAoS said in [our guidance, which was published last September.](https://www.scottishneurological.org.uk/files/a-review-of-virtual-consultations-in-scotland_september-2021.pdf)  Our number one recommendation was that patients should have choice, but this doesn’t seem to be happening in practice. This was flagged to the NACNC who are concerned this is happening. Tanith: Hadn’t realised the rare disease framework is looking at recommendations for virtual consultations. It might be worth looking at our report for some guidance. What this shows is that how managers interpret guidance is very subjective.Actions: If members do hear of others who are not getting the appointment type that meets their needs, please let us know. |
| 3 | National Neurology Patient Experience Survey- campaign summary and next steps | Tanith thanked all members for their help putting the survey link out through their networks, and Alice for her work pulling the report together.Alice: The PES was a survey that ran for the first time across the whole of the UK from October 2021 – February 2022. The methodology was sending paper copies to clinics, as well as providing an online link that our members could send out. Many thanks to everyone who sent the link out, as we ended up with over 800 respondents from Scotland which is about 10% of the UK total. This is a survey that the English Neurological Alliance does every two years, but it was the first time for us. We now have a benchmark which is really useful. We used the data that came in to understand the situation across the UK. There were some challenges with getting the data in. This isn’t uncommon but the timeframe was fairly tight. The UK data came in first so that’s what we looked at first.For the UK there is data for single condition, rare / non rare, age, ethnicity and gender. For Scotland we have data by deprivation quintile, on health boards and condition specific data. We have data for 11 HBs, with data supressed for Dumfries and Galloway, Shetland and Orkney.We have data on 35 conditions in Scotland with data breaks by 12 conditions: FND, MS, Migraine, Epilepsy, ME, Parkinson’s, Fibromyalgia, Dystonia, Myasthenia Gravis, Stroke, Peripheral neuropathy and restless leg syndrome.Three main themes were identified across the whole of the UK: big delays to treatment and care, exacerbated by the pandemic, leading to a crisis in mental health. Once people managed to get to a neurologist, a fifth of adults were getting no explanation of their condition. Significant numbers of people were not being signposted on to places to get further information for instance NHS or charity websites. We saw real distress in the lack of understanding from people who had no idea how to manage their condition without support, and people cannot self-manage effectively if they don’t have a reasonable explanation of their condition.Off the back of these three findings we made 4 recommendations, which are all in the report. However our primary recommendation is on understanding prevalence. Once we understand prevalence from the primary care and secondary care databases we can make recommendations on workforce and address the inequitable access to neurological care across Scotland.The launch of the report was on the 8th June and we presented to the MS and epilepsy CPG on Thursday 9th June. *Slide show of media also sent to members via excel spreadsheet*Following the media attention, we’ve been invited to sit at a SG roundtable on mental health as they review their mental health strategy.Next steps – are to get as many signatures on the joint petition as possible. We are approaching 5,000 signatures so far.[We have put a Parliamentary motion out which has been tabled by Monica Lennon.](https://www.parliament.scot/chamber-and-committees/votes-and-motions/S6M-04903)  We will table a members’ business motion in August and hope to get enough support to get a members debate in the autumn.Looking further ahead there is enthusiasm from all 4 Neurological Alliances to have a day of action in the Spring.Monica Lennon MSP has tabled a Parliamentary Motion for us: Thanks to all for helping get our case studies together – we couldn’t have managed the media attention without them. The case studies picked up included some rare conditions, and we were pleased to help raise awareness of under-heard voices.We want to clarify that the petition is a joint petition although the branding on it is the English Neurological Alliance only.Action: Alice to speak to the English Neurological Alliance to see if our logo can be added on, to reassure people that the petition includes Scotland.Tanith: To flag, that we have already raised the question about what will happen after the end of the framework (2020-2025) as a successor to the Neurological Framework as it is clear that given the situation with covid, that the work won’t all be done by 2025.  |
| 4 | Brain and Spine Foundation – Neuro Life Now in Scotland | Marc Smith (Brain & Spine): Thanks for inviting me to speak today and also thanks to Alice and all at NAoS for efforts to get the report written and collaborative work on the petition.Now we want to think about how to capture lived experience and the patient voice to drive forward the desperately needed changes. Neuro Life Now (NLN) was launched last year, off the back of pro bono support from KPMG. We have two objectives – proof of concept – can we reach the patient voice across all conditions, and can we find a mechanism to collect quality data to drive influence and change that we want. We have succeeded in both.We have a cut of data specific to Scotland, albeit with low numbers. We hope that with the support of the NAoS we can increase the user numbers in Scotland.We have 980 respondents across the UK, 2100 responses in that time, 9 reports published. These reports have been presented to key stakeholders in the NHS. Looking at Scottish data, by comparison to rUK it is doing better, although not good enough. Some info is as follows:* 152 respondents from Scotland Jan – Dec2022
* 44 Neuro conditions (vs 65 across the UK)
* Top 3: Subarachnoid haemorrhage, FND and MS
* Age bands: 40 – 59, with average age 49
* More women than men taking part
* Respondents reported a slightly better experience of care than in rUK
* More Scottish respondents reported that their health needs were being met compared with rUK

[Click here to read the NLN annual report](https://neurolifenow.org/wp-content/uploads/2022/04/NLN-Annual-Report-Community.pdf)The PES bi-annual survey is a deep dive snapshot every two years whereas NLN is more of a pulse – every two months.We want to use NLN to look over trends over time.Having established a platform that is gaining the trust of respondents, and which is taken credibly by the NHS and Government stakeholders, we have the ability to be agile, flexible and versatile in terms of the sorts of surveys we can put out. We can create something specific to Scotland. In this way, NLN can serve the broadest possible community. Questions:Alice: What do NAoS members need to do to be involved, and what can our member charities get out of an involvement. Can people suggest questions that go into the survey?Marc: [Our website has a lot of information](https://neurolifenow.org/) on how to be involved. We would like all NAoS organisations to promote NLN to their own communities so that everyone has the opportunity to hear about it and be involved. All data captured is anonymised. Beyond that and in terms of key issues such as prevalence, mental health, access to care at the moment we are looking at where priorities might lie based on the PES. But through the NAoS you can suggest topics for inclusion.Tanith: A question about scale – is there a ceiling on the number of participants that can reasonably be handled?Marc: At the moment we get 200 – 300 responses per survey however our ambition is that this platform allows a significant increase in the number of people to contribute their stories. With a little more automation we should be able to handle that volume in the future. Respondents are asking if they can provide more in-depth qualitative data. So, NLN is now looking into how qual data can be captured in volume.Iain McWhirter: Has there been any work done to understand what numbers are needed to be statistically significant?Marc: Initially looking at 2,000 respondents per NHS Trust would be significant (based on work by the University of Lancaster). We haven’t thought about statistical significance for Scotland. The greater the number of respondents the more holistic the picture and the more we can drill down into Health Board analysis. Keith Park (MS Soc), Our evidence team says 100 is the number we use to indicate statistical significance.Tanith: What mechanisms are in place to deal with the sampling being all online respondents given issues with disabled people being unable to access the internet in general and people in low-income communities being unable to access the internet as much as others.Marc: This is on our radar and we recognise that we have targeted the program so far to those who have access to digital channels. With the opening of clinics we may be able to pursue reaching people in other ways. We are also working with academics to see how to reach those hard-to-reach voices. Colin Robertson: Have you thought about texting people the NLN link? Headway Dundee & Angus uses texting quite frequently as a way of connecting people.Marc: Yes – this is a good idea. |
| 5 | *Comfort Break* |  |
| 6 | Members’ Update- free discussion | Member discussion about how things are on the ground currently.Ron Johnson (Epilepsy Scotland): Our clients are very concerned about the cost-of-living crisis, almost more so than Covid. The welfare rights team at Epilepsy Scotland is working flat out currently. People are also struggling to get back out socially, lots of hesitancy to go to group sessions. However, the cost-of-living crisis is having a major impact.Karen (MS TC Argyll): Our charity is at the heart of our community and we’ve set up a food larder, from surplus food from the Co-Op and any local restaurants. We also make soup and leave that for people. It has attracted lots of other people who wouldn’t necessarily come and see us or who thought we were just an MS Centre. It has been a nice way to connect the community and reduce any stigma about mental health and neurological conditions. It also reduced food waste, so it has been well received locally.Tanith: Has this involved working with other community groups?Karen: Initially we worked with [ACT](https://www.act-now.org.uk/) (Argyll Coast & Countryside Trust) who connected us with the Co-Op. We also have a piggy bank that is outside, which makes more in donations than we were out of our therapies and room hire. Ewan Dale (ME Association): Thinking about cost of living and heating costs, an overlooked point is that those with autonomic dysfunction have varying body heat control and can’t adjust body temperature by putting on another jumper. It’s a damaging change if people can’t manage in the future.Tanith: Autonomic dysfunction is almost uniquely neurological affecting lots of people in the wider community, but we are also thinking of people with wider impairments needing to keep equipment going, or medication in the fridge.How prepared do we feel for the rollout of Adult Disability Payment (ADP) on the 29th August, which is replacing PIP?Keith: We have been surveying people with MS in NHS Western Isles and Tayside (both ADP roll out pilot sites) and had a meeting with the minister last week. Turns out not many people know about it. A huge amount needs to be done to raise awareness of it, so they know it is happening. Most people don’t know what it means for them yet. We are not sure what the capacity is like at Social Security Scotland (SSS) for managing that process. Conversations previously with SG are that if people want their award reviewed they should apply for ADP. But people going through that process and with that question are being told to wait for their PIP renewal date and then get it backdated if they are due a higher award, but we have concerns about how that will work, what is the capacity to do that and support for SSS in terms of education.Tanith: It is a thing to keep an eye on as the SG decided not to have specialist advisors for neurological conditions. Are people with neurological conditions being accurately assessed? The SG are likely to be overestimating the awareness of the general public following public policy. It is also really confusion for people as those receiving PIP don’t need to do anything, but people might be anxious about the transition. It’s very hard to explain simply what is happening.Avril McClean: Action for ME and another ME charity met with the National Strategic Engagement lead for SSS and had a conversation about the difficulties with PIP relating to energy-limiting conditions. They are listening, and we’ve offered to deliver training but haven’t heard back from SSS about this.We don’t have many enquiries from people in Scotland about any support –we are concerned that people aren’t aware that this change is happening. It’s getting harder and harder to engage with people as they are prioritising their health.Keith: One more thing- those still on Disability Living Allowance, who have not yet transferred to PIP, the process for transitioning them is starting soon, but with different eligibility criteria. People will be transferred across at the same level of award for the 1st year and then reviewed. So if people are then assessed using the new eligibility criteria we’ll be in the situation again that some people will miss out. We need to make sure that people are aware of that.Tanith: The process of transitioning younger people from DLA to PIP was difficult, lots of people lost their transport because the motability rules are more generous under DLA than they are now. Thank you for sharing – it is helpful for us to have an idea of what’s happening in the wider community when we’re asked to share insights. It’s important that we’re representing all issues. At Parkinson’s UK we have been doing work around covid protection for people not on the list for boosters and antivirals. Only 4 conditions are on the list: Myasthenia Gravis, Huntington’s, MS and MND. People with other conditions can’t access those boosters regardless of clinical need. It’s still difficult for those on the list to get access to those protections, but those not on the list have no option at all. There are concerns about people being really vulnerable and remaining under personal lockdown rather than risking covid. Parkinsons UK has been writing to the CMO who say they are going to review the rationing list based on clinical evidence. It is a worry and we need to look at people being assessed on the basis of clinical need. I can’t see the difference between someone living with advanced Huntingon’s and advanced Parkinsons in terms of what happens if they get covid. Also, despite there being more people with dementia dying of covid than any other condition in Scotland, dementia isn’t on the list. |
| 7 | Mental Health discussion (breakout rooms) | Notes from this section have been written up separately but key points are:* Having a neurological condition is isolating, and those living rurally suffer more from loneliness
* Some conditions have stigma, which increases isolation (e.g. epilepsy)
* People are facing ongoing isolation and loneliness with many afraid to join face to face groups
* Many centres haven’t returned to full social function
* Lack of access to peers and of normality leads to people googling symptoms which can lead to increased stress and panic
* Challenges particularly for young people with neurological conditions are with access to mental health support – on top of anxieties with living with a neurological condition there are everyday anxieties as well
* For young people, access to CAMHS is difficult, taking too long (96 weeks in NHS Tayside)
* The long lead-in time to get an appointment or for diagnosis leads to mental health problems
* It is easiest to access mental health support at the point of crisis
* People are having to self-advocate at clinical appointments – it’s a very different experience for people now against how it was pre-covid
* People need more strategies to cope and to recover
* Rehabilitation is harder when done online- harder to understand what to do, harder to self-motivate
* More needs to be done to help people accept the impact of a neurological diagnosis
* Although there is a big cross over between neurological conditions and mental health there is no pathway to specified support – this should be addressed at diagnosis
* For conditions with known mental health or psychiatric symptoms, we need joint working between mental health and neurology teams
* Conditions with mental health issues can lead to compartmentalised support – rather than both being addressed
* People with some neuro conditions are misdiagnosed as having a mental health issue rather than the neurological issue (e.g. dystonia)
* People are often show-horned into services rather than being able to access services that meet their need
* Increasingly, charity referrals are coming through mental health services (rather than through GPs)
* The net impact of the pandemic, the cost-of-living crisis and the change to benefits is creating the perfect storm
* The priority is that we need better integration of services
* Need a stepped range of support giving access to counselling
* We also need a better idea of prevalence and awareness of what levels of support are needed for each condition
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| 8 | AORB  | There was no other business mentioned |
| 9 | The next meeting date will be our AGM on 21 September, 10.30 – 12.30 with the Minister for Mental Wellbeing and Social Care, Kevin Stewart MSP. This may be a hybrid meeting to provide an opportunity for people to meet up face to face. Please do come along! |