**Neurological Alliance of Scotland, 2021 Annual General Meeting**

**29 September 2021, 10.30 – 12.30pm**

**Minutes**

**Registered attendees:**

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| Alison Love | Ataxia UK | |
| Alistair Haw | HDS | |
| Andy Wynd | Spina Bifida Hydrocephalus Scotland | |
| Anna Telfer | Epilepsy Scotland |  |
| Avril McClean | Action for ME |  |
| Beth Strachan | CBIT |  |
| Carol Cochrane | Brainstrust |  |
| Catherine Paterson | Dochas Fund |  |
| Colette McDiarmid | MND Scotland |  |
| Colin Robertson | Headway Dundee and Angus |  |
| Ewan Dale | ME Association |  |
| Gerard Anderson | CBIT |  |
| Helen McDade | ME Action |  |
| Iain Morrison | Revive MS Support |  |
| Jackie Munro | MD UK |  |
| James Pearson | Alzheimer Scotland |  |
| John Watson | Stroke Association |  |
| Jonathan Sher | QNIS |  |
| Karen McCurry | MS Therapy Centre Mid Argyll |  |
| Katie Rigg | MSA Trust |  |
| Leigh-Ann Little | The Oxygen Works |  |
| Lorraine Jackson | Quarriers |  |
| Mary Ramsay | National Tremor Society |  |
| Michaela Regan | MD UK |  |
| Morna Simpkins | MS Society Scotland |  |
| Nancy Campbell | MSTC Lothian |  |
| Rona Johnson | Epilepsy Scotland |  |
| Ruth Richardson | Action for ME |  |
| Shirley Maxwell | Epilepsy Connections |  |
| Stephanie Fraser | CP Scotland |  |
| Stoo Brown | ME Action |  |
| Tanith Muller | Parkinson's UK Scotland |  |
| Victoria Wareham | Dystonia UK |  |
| William Oviatt | Thistle Foundation |  |

**In attendance**

Maree Todd MSP, Minister for Public Health, Women’s Health and Sport

Richard Brewster, Clinical Priorities team, Scottish Government

Anissa Tonberg, Clinical Priorities team, Scottish Government

Euan Bailey, Clinical Priorities team, Scottish Government

Declan Docherty, Clinical Priorities team, Scottish Government

Alice Struthers, Programme Director, NAoS

**Apologies**

Iain Morrison, MS Revive

**Agenda**

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| 1 | **Open, introductions and welcome from Neurological Alliance of Scotland**  Tanith Muller welcomed everyone to the meeting and introduced the Minister for Public Health, Women’s Health and Sport, Maree Todd MSP.  Due to temporary technical issues with a lack of 4g coverage in the area Maree Todd was travelling, we switched the agenda around and Tanith introduced our recent report on peoples’ experiences with virtual consultations since the start of the pandemic. |  |
| 2 | **Digital Health update: Reporting back from the NAoS Virtual Survey 2021**  Alice Struthers (Programme Director for the NAoS) presented the results of our findings from our virtual consultation survey. This survey was conducted over the summer, from 16 July – 6 August and we had 267 patient or carer respondents.  Further to the findings, NAoS is calling for 3 key changes:  1. Moving towards person-centred care, allowing neuro patients to choose the type of appointment appropriate to their needs.  2. No one should receive a life-changing diagnosis over the phone.  3. Further investment into Near Me / Attend Anywhere to minimise tech problems.  To read the full report, [click here.](https://degnish-my.sharepoint.com/personal/alice_degnish_com/Documents/Documents/Freelancing/NAOS/Virtual consultations research/Virtual Survey_Final.docx) |  |
| 3 | **Introduction by Maree Todd MSP, Minister for Public Health, Women’s Health and Sport**  Maree Todd thanked Tanith for switching the agenda around and thanked Alice for her presentation.  Maree started her speech by acknowledging the unique role of NAoS as a member organisation, and the collaboration between NAoS and the Government as critical to achieving better outcomes and quality of life for people with neurological conditions.  She reiterated the Scottish Government’s commitment to delivering the Neurological Framework. Despite the disruption created by the pandemic, funding for the Framework has been maintained and the next funding round will commence in a couple of months.  Besides funding, Maree names leadership, person-centredness and a commitment to work across boundaries with the rest of the neurological community as key to delivering the Framework.  The Government will be working directly with NHS Healthcare Improvement Scotland (HIS) to support a quality improvement approach to the implementation of the Neurological Standards and Framework. This will be supported by local leadership, and the NAoS will be called on to inform the condition-specific elements of this improvement.  Maree then addressed the issue of the workforce. The National Advisory Committee for Neurological Conditions is currently scoping workforce challenges in delivering neurological care and support, with a particular focus around staff levels and multidisciplinary team-working. The committee is also delivering guidelines for the use of digital and face-to-face consultations in neurology, which will support consistency of practice. Findings from the NAoS’ survey presented today will be taken into account.  Last month the Scottish Government launched a 5-year NHS Recovery Plan backed by more than £1 billion of investment. It is not condition specific, and besides recovery, it focuses on improving pathways of care, to enable people to be treated more quickly and closer to home. As part of Year 1 of this recovery plan, the Government have already invested £80M to support health boards targeting the backlog of care, including appointments and diagnostic testing.  In terms of workforce planning, the Scottish Government will be publishing a national workforce strategy by the end of the year tosupport remobilisation and the recovery of health and social care services, and set out priorities for recruitment, training and retention.  This period of recovery is a unique opportunity to redesign the way that we deliver care and support, and it is fundamental to making progress and achieving the vision of the Neurological Framework.  Maree acknowledges the challenges faced by the third sector during the pandemic and thanks them for their work to support people with neurological conditions. The Government is looking to embed third sector organisations as true partners in this recovery process, and to learn from their innovation, leadership and professionalism.  She reiterates her commitment to improving the treatment and care of people with neurological conditions, and to continuing the cross-working relationship built with third sector partners. Collaboration is invaluable in implementing the Framework and improving people’s quality of life. She will continue to work closely with NAoS to achieve better outcomes for people with neurological conditions across Scotland. |  |
| 4 | **Questions to the Minister from our members**  Further to Maree Todd’s talk, there was a Q&A:  Epilepsy Scotland: Roughly one million people live with a neurological condition in Scotland, but they are not mentioned in the NHS Recovery Plan or in the Programme for Government. Waiting times to see a neurologist in some health boards exceed 52 weeks. How will neurology services be supported to reduce waiting times and ensure people with neurological conditions have access to timely and high-quality support as the NHS remobilises?  **Maree Todd (MT)**: NHS Scotland is coping with a high levels of Covid-19 at the moment, with a lot of occupied beds across Scotland and people awaiting discharge. This is restricting their ability to remobilise and catch up with the backlog caused by the pandemic.  The recovery plan is not condition specific, its aim is to catch up and get the system working again for everyone, regardless of their condition. This should improve the situation for people with neurological conditions.  We are also looking at new ways of working, and the Centre for Sustainable Delivery has been involved to support NHS Scotland and the broader health and care system, to make the system more effective and sustainable, through the efficient delivery of modern, high quality, patient-centred services.  This includes modernising patient pathways, and full adoption of those programmes will reduce demands for outpatient appointments and increase outpatient capacity. The challenge is making this change at a time when there is such immense pressure across the system.  Cerebral Palsy Scotland: We know from our work on the National Advisory Committee for Neurological Conditions that community support and rehab was really challenging pre-pandemic, and given your point that people are stuck in hospital because they can’t be discharged, shouldn’t we be concentrating more, particularly with budget and supporting workforce, on supporting community rehabilitation rather than sending things to be lost in NHS boards budgets per se?  **MT**: Yes, one of the reasons for the plans around the National Care Service is we know it wasn’t working for everybody pre-pandemic, especially for young people with neurological conditions. The pandemic has shone a light on pre-existing difficulties, and a lot of the current work of the Government is about making a National Care Service that is equitable across the country.  In addition to social care provision, we want to improve primary care and services, because it should be about accessing the right services at right place at the right time; it shouldn’t always be about having to travel to a hospital. Many of my constituents live hundreds of miles from the local hospital. With all the caveats around virtual appointments, the first question every time should be “Is that journey necessary or could it happen closer to home?” And I think that could really improve quality of life.  QNIS: QNIS is one of the only members of this Alliance that is not condition-specific. Our job is to support and assist community nurses – a workforce of about 50,000 – in every corner of Scotland, the majority of whom deal with people having neurological conditions. So strengthening the community side of the equation is a crucial piece of the work. I wanted to bring to your attention the degree to which the Framework and Action has not given full weight to the importance of prevention. It is essentially after the fact pathways, services and activities. All of which are crucial and I would never diminish their importance, but in a situation where resources, staff, and the whole system is incredibly burdened, part of solution comes by turning off the tap. So that there’s not an endless supply of people needing help with neurological conditions, some of which were preventable. This didn’t have much priority in framework, and given that this is the 10th anniversary of the Christie Commission report, that pointed out 40% of public expenditure goes to cleaning up messes that could have been prevented. 10 years later, what are we going to do on the prevention side?  **Chair**: There was widespread celebration in the neuro community about the decision around folic acid fortification, as a really good example of something that is preventative and will make a real difference. Maree, have you got some brief comments on the place of prevention?  **MT**: We are determined to tackle non-communicable diseases, especially because of the level of inequality in the experience of those diseases. I’ll be looking for support from all of you to be able to take some bold steps to tackle all unhealthy behaviours in Scotland.  The thrombectomy service for people suffering strokes is a great example of a treatment that is also about preventing disability afterwards.  Finally, there has been massive behavioural change with the pandemic. One of the plusses that may come is an increase in health literacy and self-efficacy. People are navigating data in a way they didn’t in the past, they’re looking online and looking at the level of the virus in their community, making risk assessments. We can capitalise on that to improve people’s ability to look after themselves and prevent illness.  MND Scotland: How can we ensure the National Care Service can respond quickly enough to the needs of people with rapidly degenerating and terminal neurological illnesses like MND?  **MT**: One of the real challenges of MND is that it is so fast moving that people struggle to keep up with the changing needs of the individual.  The National Care Service consultation is open and intended to start a discussion about what we need from our social care system, to ensure people can access support. We want to work with organisations like yours to make sure what is delivered works for people with conditions like MND. We want to hear directly from the people affected, exactly what challenges they face.  We are currently working on accessible housing, housing adaptation, assistive technology, and care at home. We set out in the Housing 2040 Strategy how we’re going to streamline and accelerate the adaptation system, to reduce the time it takes to apply for and receive support.  And we need to be thinking about anticipatory care planning at a much earlier stage, not just around the process of end of life care, but for a changing picture, for a progressive illness. Should there be a rapid deterioration in a patient’s situation, how does that individual want their social care to happen? This discussion needs to be had in a sensitive way that puts the person at the heart of it, ensuring they are empowered to plan it and decide how they would like their care to progress.  **Chair**: These comments about anticipatory care planning will be really welcome across the sector. Neurology professionals have been a bit reluctant to talk about deteriorating health, particularly for people who have slower progressing conditions. And the act of ageing with a stable neurological condition also means people need to plan for deteriorating health as they age. The recent round table education event that NHS Education for Scotland organised, with health professionals talking about anticipatory care planning, was a really welcome development in terms of shifting some professional understandings about the need for this.  ME Action: In 2011, the Scottish Public Health Network published its Healthcare Needs Assessment of services for people with ME-CFS. In 2020, the Network reaffirmed that the measures were still needed. We are expecting the long-awaited NICE Guideline on ME to be published soon. 10 years after the Health Care Needs Assessment, people with ME in Scotland are still waiting for services to meet their needs. Will the Minister commit to implementing the Health Care Needs Assessment recommendations, and tell us when and how they will be implemented?  **MT**: Collaboration is vital to our work. We welcomed the updated healthcare needs assessment published earlier this year. It’s a really important document setting out some of the difficulties facing people living with ME-CFS. We recognise the recommendations it makes, and many are already explicitly in line with the current commitments in the Neurological Framework, the scope of which covers ME-CFS.  One of our first steps is reviewing and updating the Scottish good practice statement on ME-CFS that takes into account the new NICE guidelines when they are published. We were disappointment to hear NICE guidelines have been paused. NICE is meeting with stakeholders in October to better understand the issues raised and resolve them. We continue to actively work with the third sector and clinical stakeholders in Scotland to review what care and support is needed, and plan improvements for people living with ME. We are also taking into account the recommendations in this report and in the ongoing delivery of the Neurological Framework. I’m afraid I can’t give you a specific time, but we are not waiting for NICE to come along before doing anything, and we are expecting the challenges they are facing to be resolved in the next few months, so we are expecting pretty rapid progress.  **Chair**: It’s a big issue for ME organisations represented in our membership, the ME community has felt really neglected for a long time in terms of care, it’s important for these needs to start to be met.  HDA: A University of Aberdeen study published in the Journal of Neurology has shown that the number of people with Huntington’s disease (HD) in northern Scotland is now five times the global average having increased by almost 50% over the last 30 years. Similar increases have been experienced throughout Scotland.  International evidence shows that that investing in specialist HD support is a classic example of spending to save. The cognitive and mental health symptoms of HD can result in clients having no insight into their own condition. A proactive approach from specialist staff who understand HD prevents crisis situations from arising. This reduces emergency admissions to A&E, and onwards to hard pressed and costly acute services.  Does the Scottish Government accept that cutting specialist services for HD (and other neurological conditions) is a huge mistake and a false economy and, if so, what is it doing to ensure NHS Boards and HSCPs looking to save money as we come through the pandemic are aware of this position to prevent them from finding out the hard way?  **MT**: I come from the part of country that has the highest rate of Huntington’s in the world. It is a condition I am familiar with, and I really appreciate the work you do. We absolutely recognise the importance of specialist services for neurological conditions like Huntington’s. That’s why for the last 6 years the Scottish Government provided £2.4M each year to improve specialist nursing services. We funded £240,000 to date to develop a National Care Framework for HD. We’ve also contributed towards the Scottish Huntington’s network association of specialist for individuals and families.  We absolutely understand the importance of preventative spending on the right care approaches and want to explore whether those community-based models of care, used in some neurological conditions and services, could be expanded to cover more. The Neurological Framework specifically commits to working with all of you to explore the potential of National Care Frameworks, and how these could inform neurological care and support. We are prioritising the development of local improvement and leadership networks for neurology, to foster quality improvements and share priorities for neuro conditions.  We are working with the NHS to insure the implementation by boards and HSCPs of the general standards for neurology. We are looking to take a cross-sector approach and generate condition-specific intelligence to inform local planning. All of you are going to be vital to ensure we deliver a patient-centred approach on the ground, so local services are developed with you at the heart of them.  HDA: Are you able to clarify what you’re doing to ensure HSCPs and NHS boards are aware of your support for specialist services?  **MT**: We are clear that specialist services are vitally important. There is no decrease of support from the government, and if that is the perception on the ground or at board level, we can certainly put forward some evidence, and I will see what I can do to help you tackle that. I know from my own health board, because of the pandemic there have been disruptions to awarding contracts and service agreements and for many months have been patching together services with 3rd sector organisations, which is profoundly unsatisfactory for everybody involved. I hope quite soon we can get on a more even footing, and plan for several years ahead, in the way we know delivers the best for people in organisations, and people on the ground who need your services.  **Chair**: A question from Ataxia UK about cross-border care and support for people with a rarer condition. What commitments can you make on cross-border care for people who need expertise that is not available in Scotland?  **MT**: This is one issue that would be improved by modernising patient pathway care, so that we have the same referral process across Scotland. I imagine this is one of the areas where there’s a variation across the country, and people are experiencing very different level of access and processes. Modernising patient pathways is the way we’re going to reduce the level of variation, and make sure people get efficient and rapid access to the specialist care they need. There shouldn’t be a problem with cross-border referrals. If we don’t have the expertise in Scotland it’s perfectly appropriate that people are referred to tertiary services in other parts of the UK. The challenge is bureaucratic, and making that bureaucratic process work quickly enough for individuals who need to access these services. Again I would expect the work with HIS to help on that. And all of you as third sector organisations will need to speak up and talk about the particular area that affects your communities, to make sure what we put in place works for people you are working for.  End of Q&A. The Chair will forward further questions from members to the Minister, who will answer them in writing. |  |
| 5 | **Member discussion: What key actions can change lives?**  **Maree Todd**: I would like to hear about one or two key changes you think could make a tangible difference to the people you are representing?  Essential Tremor: We are calling for a review of the National Services Division (NSD), and specifically the specialist services committee of NSD which is the body that decides on specialist treatment. They need to give the NHS the green light to fund focused ultrasound treatment for people with essential tremor, because in the future this could help people with other neurological conditions. The NSD have been the barrier to putting this treatment in place.  **MT**: I agree. We need to move to a person-centred, flexible, holistic service which provides care in the right place, at the right time, from the right people. I hear from many people who are not experiencing that on the ground. So much of our focus is on making that shift in the NHS.  **Chair**: The Scottish Government has worked on making the Scottish Medicines Consortium more transparent, but if the treatment needed is not medical but surgical or technology based, then the decision for this treatment seems much less transparent and easy to understand.  Cerebral Palsy Scotland: People with Cerebral Palsy make up 10-12,000 people in Scotland, but there are no specialist clinical nurses or neurologists. It’s a life condition but it is seen as a static condition, because nothing can be done to make it go away. As people grow older their CP impacts them far more, so I am asking for annual reviews. We’ve seen more people during the pandemic who in normal time work, are able to manage their own condition, but when under stress – that’s when they need a review. And you can’t always assess, if you’re declining slowly, that you are declining. So early intervention is needed. In England there are NICE guidelines for adults with CP, can we please have a Scottish version, and can we please have annual reviews.  Parkinson’s UK: We would highlight the issue of workforce. We are relieved it’s being tackled, but it is a really longstanding problem in neuro services at every level, from community writeup to consultants. It is of concern that neurological conditions remain on the fringes of being a Scottish Government priority, but never quite making it to the top line.  Child Brain Injury Trust: You are aware of the impact of sports concussions and the long term effect of concussions. Families say they wish we were there in hospital whenever they receive this diagnosis, or that they had more information on discharge. It would be great to focus on discharge process from acute care to the community, and ensuring when patients are discharged after a diagnosis that they’re given accurate information, literature and follow-up resources. So if they go on to have longer term support needs they will know where to go.  **MT**: You’ve highlighted one of the challenges in the entirety of system, which is that transfer between secondary and primary care. Sometimes the information doesn’t flow and the care isn’t right, often in these situations people can’t take in the information, so we need to think about interface.  MS Therapy Centre Lothian: Speaking about early intervention pathways, some of the issues faced by provider charities who work with the NHS are that the NHS does not always recognise the expertise, services and support available in the 3rd sector.  Parkinson’s UK: Agree with above point, new patients are discouraged from attending the charity’s local groups to prevent them from seeing people with an advanced condition. Thus making the decision for the patient, if they’re told about the services at all.  QNIS: We must recognise that neurodevelopmental conditions are neurological conditions. They are life-altering and lifelong. As a pharmacist you know about valproate and foetal valproate spectrum disorder. Despite its name, it does not just affect babies, it is a lifelong condition. But it is not dealt with as one in the Framework or in practice. The Scottish Government estimates that 172,000 people – children, young people, adults – are affected by Foetal alcohol spectrum disorder (FASD), yet less than 1% have ever been diagnosed or given adequate treatment and support. The issue is even when known conditions are a stressor, to recognise there are still blind spots that affect individuals and society.  **MT**: Absolutely right. Prevention during pregnancy, including FASD and valproate harm, is really important. I was involved in the guidelines which first recognised the valproate harm and the link with autism and the other teratogenicity. It’s a passion of mine to be thinking early on to ensure we have healthy pregnancies and healthy babies born.  The Chair thanks the Minister for spending time with us, answering questions and listening to various comments.  **MT**: Thank you for your time today, I am looking forward to a long and fruitful relationship.  End of the Members’ meeting. |  |
| 6 | **Annual General Meeting Business**   1. Apologies   Ian Morrison, MS Revive   1. Minutes for AGM 2020 (attached)   No amendments raised.  Decision: the Minutes are approved.   1. Annual Report and financial statement for the year to March 2021 (attached)   The Chair presents accounts for 2020-2021. Covid disruption led to substantial excess at end of the year.    Decision: The accounts are approved.  Key points of Annual Report:  Membership: At 31 March 2021 we had 51 members of NAoS. During 2020-21 we welcomed 9 new members. We also identified inactive members and terminated their membership. The focus is on active membership and having an influence on a wide range of people.  Key areas of activities:   * “Living through Lockdown” report produced in summer 2020 * Developing 3-year strategy after consultation with membership: to inform, connect, and influence. * Mapping membership to understand their work. This gave us a more thorough understanding of the neurological third sector in Scotland. * Representation on National Advisory Committee and other Scottish Government bodies. Alistair Haw and Alice Struthers are now working with ScotGov on its workforce planning.   Next steps: NAoS will keep growing its active membership, and make sure the needs of neurological community are met as we come out of Covid.  Decision: The annual report is approved.  New guidance for carers:  Alice presents new guidance produced by NAoS Carers subcommittee for carers of people with a neurological condition. There are three new resources available on the website.  The rationale is that there were existing carers resources but none specifically for neuro conditions.  Promotion: Anissa at ScotGov will put them out to her contacts and will try to get our members to promote it. Coalition of Carers in Scotland have been very supportive.   1. Resolution on proposed changes to the Neurological Alliance (SCIO) constitution (attached)   Eight amendments were proposed to the constitution and all were adopted. Members voted by Zoom poll during the meeting.  The amendments include:   * Reflecting the reality of hosting events online, allowing for the virtual presence of the members, executive, Chair and any guest speakers. * Updating language to become gender-neutral. * Increasing the number of executive members from 12 to 14, two of which can be co-opted from outwith the membership. * Changing the termination of office rule: a trustee who misses 3 executive meetings in a 12 months period will automatically cease to hold office.   Decision: all amendments approved.   1. Proposed fee band changes (attached)   Organisation’s income of under £50,000: £0  £50,000-£100,000: £50  £100,000-250,000: £100  £250,000-500,000: £125  £500,000-10M: £175  Over £10M: £250  Vote through Zoom poll: 86% in favour of change.  Decision: the new fee bands are approved.   1. Election of Executive Committee (applications attached)   We are still looking for executive members and people are welcome to stand during the AGM. We particularly welcome interest from anyone who feels they have something to offer and from smaller charities who can help us reflect diversity in the neurological community.  Iain Morrison (Revive MS Support) resigns from the executive.  Applications received from Alison Love (Ataxia UK), Ewan Dale (ME Association), Tanith Muller (Parkinson's UK) to renew their 3 year term; and new applications are made by Stoo Brown (ME Action), James Pearson (Alzheimer’s Scotland) and Carol Cochrane (Brainstrust).  Decision: All the above candidates are elected to the executive for a 3-year term, making the number of trustees 11. There remains 3 vacant seats, 2 of which are also open to independent candidates (non-members).   1. AORB   None   1. CLOSE of meeting | |

There will not be an Executive Meeting following the AGM.