NAoS Members Meeting Summary

25th March 2021

10 – 12pm Online Via Zoom

Present:

Tanith Muller, Chair, Parkinson’s UK

Rona Johnson, Vice Chair, Epilepsy Scotland

Ewan Dale, Exec member, ME Association

Gill Dickson, Exec member, PSPA

Lucy Harmer, MS Trust

Mary Ramsay, Scottish Tremor Society

Angela Feherty, MS Revive Support

Keith Park, MS Society

Carole Cochrane, Brainstrust

Colin Robertson, Headway Dundee & Angus

Catherine Paterson, Dochas Fund

Jackie Munro, MDUK

Stuart Brown, ME Action

Helen Madonald, Lanarkshire Epilepsy

Phil Robson, Lanarkshire Epilepsy

Melissa, Tourette Scotland

Avril McClean, Action for ME

David Mulligan, Funding Neuro

Karen McCurry, MS Therapy Centre, Mid Argyll

Katie Rigg, MSA Trust

Sue Millman, Ataxia UK

Jonathan Sher, QNIS

Victoria Wareham, Dystonia UK

Gerard Anderson, CBIT

Michelle Keenan, Headway Edinburgh

Becky Duff, Programme Director NAoS

Alice Struthers, Programme Co-ordinator NAoS

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| 1 | Chair’s welcome and Scottish Government update | Tanith agreed to circulate materials from the CMO about vaccines relating to the change to the ‘evolving neurological conditions’ instruction (attached to email)  The Patient Safety Commissioner consultation was also flagged up, relevant to epilepsy and the use of sodium valproate in particular. (This is linked in our March newsletter) |
| 2. | NACNC update | Discussion of NHS Inform and the intention to prioritise neurological information going forward. Where there are gaps in information caused by lack of staff capacity, it may be that staff on furlough can step in and work with the NHS Inform team. This would suit someone in a Comms role.  In addition, there’s work ongoing on prevalence by checking what is coded by SPIRE (Scottish Primary Care Information Resource). Scottish Govt are looking at SPIRE codes (recognised not to be accurate, but a good starting point). Some concern raised by NAoS members including QNIS: the problem of underdiagnoses or misdiagnosis will not change unless and until the SG and NHS - and GPs - are more active in including, and acting on, these neurological conditions.  ME Association: We want to compare ME/CFS codings with FND codings for the probable overlap / mis-attribution  MSA Trust: SPIRE codes are used by GPs, why is the SG not looking into ICD10 codes? |
|  | NACNC actions | MSA Trust flagged up that this may be an overlap of work underway in England with ICD10. NAoS to flag up with SG. |
| 3. | Members’ check in | Epilepsy Scotland – issues with vaccines being refused to those with epilepsy have been levelled out, with a corresponding drop in anxiety on the helpline.  MS Society – Issue particularly in the Borders with those who were turned away initially (due to having a neurological disorder), still being unable to get their first appointment.  Action for ME – confirmed there’s still a postcode lottery for Covid vaccine, with many hotline calls still relating to lack of access.  Ataxia UK – Some concerns raised about the viral vector being used in the Covid vaccine, in case it doesn’t work with genetic therapies. |
| 4. | Mapping Survey Presentation | NAoS presented the mapping survey (Powerpoint attached to this email) and mentioned the work done on taking raw data from the survey and creating a condition/service spreadsheet by health board (also attached to this email). |
|  | Mapping Survey actions | Recognition that there could be errors, in addition to missing info from those who didn’t respond to the survey. Could all those listed in the excel document check the data for errors, and could all those who did not take part in the survey, send in their service provision by health board. Full details will be laid out in the email. |
| 5. | Questions on Mapping | Recognition that certain terms such as ‘self-management’ and ‘navigation pathways’ were not fully mapped as these are not ubiquitous terms. Many people self-manage without consciously thinking of it as self-managing (for instance, going for walks, yoga, breathing slowly etc), and therefore not reporting to charities that they are self-managing. As the ME Association said: People read and adapt info on self-management rather than get involved in formalised service delivery? We ran two polls during the presentation, the first was whether charities have a condition-specific self-management tool (majority ‘no’) and the second was whether people knew what a navigation tool was (large majority ‘no’). |
| 6. | Strategy Review | Becky Duff gave a presentation on the strategy development and the attendees were split into 4 breakout rooms for focus groups, to look at the core strategic themes: Inform, Connect, Influence. |
| 7. | Feedback from Focus Groups | INFORM  -  largely +ve about this - members felt this was the starting point for everything else. But some discussion as to whether ‘awareness’ would work better.  - Role for NAoS in informing clinicians about neuro conditions  - as well as members of the public and the SG  - Sustainability of informing needs to be considered (e.g. resources spent informing one cohort of GPs has a limited timespan before the next cohort need informing).  - Lots of discussion about the Neuro HUB idea, as a way of amplifying existing resources. There was some concern that NAoS lacked capacity to create its own resources so helpful to provide access to useful resources created by members.  - Mental health is an important issue and undoubtedly worsens peoples’ experiences of living with a neurological condition. Members would like NAoS to push more on this, to drive up mental health services for people with neuro conditions  - Role for NAoS to lobby/inform SG on neuro workforce requirements so that long-covid care doesn’t absorb the existing neuro workforce  CONNECT  - Connect was particularly important to make sure no one is reinventing the wheel and the neurological community voice is strengthened  - Discussion about potential hosting for charities working with same / similar conditions - eg MS, brain injury - could NAoS provide support for information sharing if needed?  - Covid context makes connecting more important than ever.  - Strong demand for contact details of attendees and orgs to be shared and accessible to members to enable contact and collaborations to flourish outside meetings  - Members would like to be connected more with clinicians, specialists and GPs, to improve the pathway to third sector  - agreed that Neuro Hub could be a good avenue for this if promoted properly with GPs and specialists  - self-management is at its best when it involves connecting people living with the same neurological conditions.  - NAoS to help with connecting with the right people (particularly on the statutory side)  INFLUENCE  - Influence should be at a Government level but also clinical  - Good discussion about potential subgroups - including a strong case around children and young people policy as there are particular needs to address as Framework does not cover children apart from transitions. |
| 7. | Feedback from Focus Groups | Please can anyone with any additional comments on the Strategy Review, get in touch with Becky Duff directly via her email: rebeccaduff04@gmail.com |
| 8. | AORB | No AORB |
| 9. | Next dates and close of meeting | TBC |