**National Advisory Committee for Neurological Conditions (NACNC) minutes**

**23 November 2023, Microsoft Teams**

**Attendees**

Stephanie Fraser (Chair) (SF), Cerebral Palsy Scotland

Susan Walker (Deputy Chair) (SW), NHS Greater Glasgow and Clyde

Dr David Breen (DB), Consultant Neurologist, NHS Lothian

Dr Callum Duncan (CD), Consultant Neurologist, NHS Grampian

Wendy Forrest (WF), Clackmannanshire & Stirling Health & Social Care Partnership

Jennifer Hall (JH), Deputy Chair of the Neurological Alliance of Scotland (NAoS)

Stephanie McNairney (SM), National Centre for Sustainable Delivery, NHS Golden Jubilee

Judith Newton (JN), National MND Nurse Consultant - University of Edinburgh (covering all boards)

Morna Simpkins (MS), Chair of NAoS (from 10:00)

Dr Maggie Whyte (MW), Consultant Clinical Neuropsychologist, NHS Grampian

**Scottish Government (SG) Officials**

Keith Willcock (KW), SG - Clinical Priorities, Team Leader, Neurological Conditions

Richard Brewster (RB), SG - Clinical Priorities Policy, Framework Delivery

Anissa Tonberg (AT), SG – Clinical Priorities Policy, Neurological Conditions (from 10:00)

Craig Kennedy (CK), SG – Clinical Priorities Policy, Neurological Conditions (Minutes)

Euan Bailey (EB),SG – Clinical Priorities Policy, Neurological Conditions

**Meeting Guests**

Dr Craig Heath (CH), Consultant Neurologist, NHS Greater Glasgow and Clyde

**Apologies**

Dr Jenny Preston (Deputy Chair), NHS Ayrshire and Arran

Will Wood, SG – Unit Head, Clinical Priorities

**Items and actions**

1. **Welcome, Introductions and Apologies**

The apologies were noted from the above.

New members of the group were welcomed. Jennifer Hall, the new Deputy Chair for the Neurological Alliance of Scotland (NAoS) and Craig Kennedy, a member of the Neurological Conditions Team at the Scottish Government.

1. **Minutes and Matters Arising from Last Meeting**

The Committee confirmed that the minutes reflected an accurate record of the previous meeting of 24 August 2023.

A response from the Head of Service, Information Delivery, at Public Health Scotland (PHS) regarding disease prevalence was circulated to NACNC members ahead of the meeting.

RB updated on NACNC recruitment. SF encouraged members to contact RB if they could provide assistance in progressing this.

1. **Scottish Epilepsy Register**

SF introduced CH to give a brief overview of the Scottish Epilepsy Register (SER).

Scottish Epilepsy Register is now active in NHS Greater Glasgow & Clyde (GGC). It uses data to improve care and outcomes for individuals with epilepsy and provides alerts for key adverse clinical events.

A 12 month audit of data has identified fuller medical information of patients: women with epilepsy (WWE) who are pregnant, PWE who have recently attended Accident and Emergency (A&E): analyse data relating to access to care, medication adherence and dispensation.

After funding for this project through Round 1 and Round 2 of the Neurological Care and Support: Framework for Action 2020-2025 (‘Framework’), CH and his team are looking to expand the digital dashboard into NHS Ayrshire & Arran and NHS Lanarkshire in 2024 and roll out across all Boards nationally beyond that.

Paper 2 outlines the work in 2 phases:

1. Implementation and adoption across Scotland
2. Incorporation to Scottish National Audit Programme (SNAP).

One key advantage is the prioritisation of need. Routine clinics do not enable this. Work on streamlining pathways is still progressing though the level of nurse specialist resource is not increased. It is just used more effectively.

The Committee was supportive of the need to prioritise the national roll out. There was less certainty about the value for money incorporation to SNAP represents and this might need further exploration.

**ACTION 1: RB agreed to look at this further to identify the exact requirements and associated costs around the adoption and incorporation into SNAP.**

**ACTION 2:** **CH agreed to review approaches to agreeing eHealth leads support for national roll out of SER.**

**ACTION 3:** **RB to seek endorsement from Deputy Director, Digital Health & Care, Scottish Government of alignment of SER with national digital strategy.**

**4. Framework progress update**

* **Written update**

RB highlighted eight projects awarded funding under Round 4. The Scottish Government website listing all awards across four rounds has been updated, and provide links to final reports where available.

NAoS have had discussions around National Care Frameworks (Commitment 10). Progressive Supranuclear Palsy Association and Multiple System Atrophy Trust are interested in developing an NCF for their conditions.

* **2023-2024 Delivery Plan**

The paper detailing the 2023-24 Delivery Plan was noted. It was noted that references to Redesign Project Group should be replaced with Service Improvement Forum.

* **Service Improvement Forum**

The Service Improvement Forum (SIF), at its last meeting, had presentation from Wendy Carswell, a pharmacy Clinical Improvement Fellow in NHS Lothian. Her work makes recommendations, including the development of a pharmacy Special Interest Group for neurology, and reviewing the skill mix in pharmacy. SIF has asked for regular progress updates on this work and offered to support the development of the network.

The Committee felt there would be a strong benefit from having a pharmacy representative on SIF and RB agreed to write back to Wendy and Arlene Coulson, a neurology specialist pharmacist from NHS Tayside confirming this.

**ACTION 4: RB agreed to reach out to Wendy Carswell and Arlene Coulson to confirm representation on SIF.**

SW advised the group that the Clinical Nurse Specialist (CNS) Census report should be available in December 2023, with 13 out of 14 Heath Boards, and two Special Boards responding to the survey. The report data covers all nurse specialisms (not just neurology).

Expressions of interest have been received for the NHS Education for Scotland (NES) commission to undertake nurse competency mapping. A decision on who takes this work forward and the governance structure for it will be finalised soon.

**5. Self-evaluation of Neurology Standards**

To support the self-evaluation of neurology standards 'Touchpoint’ sessions had been held for NHS boards, Health and Social Care Partnerships. An additional session was held with staff from NHS Greater Glasgow and Clyde. They have agreed to focus on MS services across GGC in the first instance. It was noted that this might be a more realistic approach for large NHS boards. Two more sessions will also include the third sector will be held in late November / early December.

There was discussion around the potential quality of returns from each Board, noting that this may make a consistent and measurable evaluation process more challenging. The Committee is mindful of the current winter pressures facing clinicians involved in this work and will be sympathetic to when and how returns are received. It was agreed to continue to work with NHS boards to monitor the manageability of the deadline. More work will need to be done to assess the volume of returns to prepare the analytical capacity.

RB informed the group that two individuals have been recruited to ‘Network Coordinator’ roles in the ‘East’ and ‘West’ regions of Scotland to assist both Boards and the third sector in evaluating their services. The successful applicants, with experience in service evaluation, engagement and management skillsets, are expected to commence in January 2024.

**6. Engagement for Post Framework**

The Committee began initial discussions in planning after the ‘Framework’, which comes to an end in March 2025. There is a need to define objectives beyond this date.

The Committee reflected on their role as an operational and strategic body and whether this had been effective.

The Committee were mindful of the likely impact and influence of the National Care Service development on how neurological services are delivered.

The need to prioritise engagement before distributing a document was emphasised. The timing of the Scottish elections in 2025 also needs to be considered as part of the process.

It was highlighted that the self-evaluation process will begin to build a picture of neurological services in Scotland and this will help the Scottish Government to identify both positive areas of care, as well as areas for improvement.

There was a suggestion that a ‘self-evaluation report’ from the Committee could be produced, including personal stories of how the Framework has impacted opportunities to develop and improve neurological care. It was suggested that NAoS could help coordinate this.

**ACTION 5: RB to amend the process based on comments and discussion.**

**7. Progress on related strategies**

KW summarised his report which provided overall context in which the Scottish Government is working, and how the Committee could link in with other priorities around Health and Social Care – notably the Dementia Plan and the National Care Service.

JH highlighted her work with Alzheimer’s Scotland and will be able to link with work around the dementia plan.

It was noted that while the safe staffing legislation was important, it has the potential to result in services having to be removed due to lack of safe staffing.

Work on workforce planning tools and the AHP Professional Judgement Tool support safe staffing legislation. Without the necessary funding staffing gaps cannot be filled.

RB informed the group that the Scottish Government team who lead on Proactive and Preventative Care Programme would be willing to speak with NACNC members at a future meeting. It was agreed that this would be discussed further with NACNC Executive in the first instance.

1. **AOCB**

Meetings for 2024 will be issued to NACNC members in early December 2023.

**Review of Action Points**

|  |  |  |  |
| --- | --- | --- | --- |
| **No.** | **Action** | **For** | **Progress** |
| 1. | RB to look to identify the exact requirements and associated costs around the adoption and incorporation of the SER into SNAP. | Richard Brewster | **To be progressed.** |
| 2. | **CH agreed to review approaches to agreeing eHealth leads support for National roll out of SER, with RB seeking endorsement from Digital Health & Care team in the Scottish Government** | Craig Heath / Richard Brewster | **Ongoing - Incorporated into Business Plan / Continued engagement with eHealth leads.** |
| 3. | RB to get in contact with Arlene Coulson (Pharmacy) and Wendy Carswell () to confirm their representation at SIF | Richard Brewster | **COMPLETE – AC has joined the SIF and nurse competency mapping group.** |
| 4. | RB to amend the Post-Framework process following discussion at November 2023 NACNC | Richard Brewster | **To be progressed** |

Date of next meeting: 29 February 2024, 10:00-12:00