

NATIONAL ADVISORY COMMITTEE FOR NEUROLOGICAL CONDITIONS (NACNC)

MINUTES

29th November 2018, St Andrew's House, Edinburgh

Present

Dr Richard Davenport (Chair)	NHS Lothian
Stephanie Fraser (Deputy Co-chair)	Bobath Scotland
Colin Urquhart	Scottish Government
Gerard Gahagan	Neurological Alliance of Scotland
Alison Love	Representative of Service Users
Dr Jenny Preston	NHS Ayrshire and Arran / IJBs
Gregory Hill O'Conner	The Health and Social Care Alliance
Jane-Marie Stobie	NHS Lanarkshire
Dr Jonathan O'Riordan	NHS Tayside
Kirsty Forsyth	Scottish Government, NACNC Project Coordinator
Annie Macleod	Parkinson's UK
Kerry Morgan	Scottish Government, Head of Clinical Priorities

Attending by Telephone Conference

Sandra Larkin	NHS Tayside
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Apologies

Prof. Siddarthan Chandran	University of Edinburgh
Prof John Paul Leach	University of Glasgow/NHS Greater Glasgow & Clyde
Dr Callum Duncan	NHS Grampian
Irene Oldfather	The Health and Social Care Alliance
Susan Walker (Deputy Co-chair)	NHS Greater Glasgow and Clyde

1.	Welcome, Introductions and Apologies Dr Richard Davenport welcomed everyone to the meeting. Apologies were noted as above. Dr Richard Davenport also advised the committee of the resignations of Dr Ed Newman and Dr Craig Heath, Scottish Association of Neurological Sciences (SANs) / NHS Glasgow & Clyde, who demitted office as they are no longer co-chairs of SANs. It was also noted that Claire Ritchie, co-chair of the Parkinson's Sub-group had resigned, as she had moved from	
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	NHS Lanarkshire to a new post with NHS Greater Glasgow & Clyde.	
2.	<p>Minutes of Previous Meeting The secretariat was advised that Dr Leach should be corrected to read Professor Leach.</p> <p>Matters Arising Getting It Right First Time Dr Davenport advised the committee that progress on this was slower than expected, however some reports for other specialties had now been published.</p>	Secretariat
3.	<p>National Action Plan on Neurological Conditions (Draft for Consultation) 2019 – 2024 NACNC 29112028 -03</p> <p>Dr Richard Davenport referred to the discussion on the draft at the previous NACNC meeting, and noted that the project team had done a lot of hard work before the plan had been passed to Scottish Government and aligned with the usual style for Scottish Government documents.</p> <p>Dr Richard Davenport encouraged people to read the full document, as it contains a lot of detail, and noted that we want to encourage people to read and comment in the consultation.</p> <p>Dr Jenny Preston has been asked to lead a session on the HIS Standards and the National Action Plan(NAP) at the next MS cross-party group meeting, and commented that some people have asked if the consultation is truly a consultation.</p> <p>Ms Kerry Morgan and Mr Colin Urquhart gave assurances that Scottish Government will act on feedback received through the consultation process, and that this is line with the partnership approach which has developed the plan thus far.</p> <p>Other comments received by some members of the NACNC concerned whether the NAP was too strategic, and mentioned specific omissions such as counselling and alternative, augmented communication (AAC).</p> <p>Mr Gerard Gahagan reported that the Neurological Alliance of Scotland had not made any criticism of the NAP so far, as people are impressed by the strong commitments and relatively positive about the plan. Ms Stephanie Fraser agreed that it had been well received to date.</p> <p>Dr Jonathan O’Riordan commented that in Tayside, young people move to adult neurology services at 14. There was a</p>	

	<p>discussion about the age range of children’s and adult services. Dr Richard Davenport considered it advisable that young people should remain in paediatric services until at least 16 years of age. There was further discussion on this point, with some suggesting young adults could remain in paediatric services beyond 16 years of age.</p> <p>It was noted that the Scottish Huntington’s Association National Framework had been endorsed by NACNC.</p> <p>The committee noted the need to be explicit that the consultation on the NAP is separate from the consultation being carried out by HIS on the General Standards for Neurological Care and Support.</p>	
<p>4.</p>	<p>Consultation Communication Plan NACNC 29112018 – 04</p> <p>It was agreed that the communication plan for the consultation would be amended to include sending out a reminder in the new year.</p> <p>Dr Jonathan O’Riordan asked about funding for self-management in relation to commitment 1 in the NAP. There was discussion on what funding would be available to NHS Boards to support commitment 1 and the other commitments. It was recognised that the wording in this commitment may need to change as it was being interpreted in different ways.</p> <p>Ms Kerry Morgan noted that work is ongoing within Scottish Government to develop and identify other sources of funds. Mr Colin Urquhart gave the example of waiting times improvement plan funding, which is not held by the Clinical Priorities team, however has been identified to support rapid access neurology clinics. Ms Kerry Morgan assured the committee that money will be available when we have identified what needs to be done, however the actions in the implementation plan may not be resource dependant, and would need to recognise the tight financial climate.</p> <p>Ms Stephanie Fraser suggested that funding may encourage IJBs to support change. Ms Stephanie Fraser then enquired whether the timescales for the consultation would have an impact on funding decisions. The committee noted that the 4 week timescale for analysis was potentially challenging, and may extend to 6 – 8 weeks. As the implementation of the NAP is already in the Programme for Government, the secretariat did not think any slippage in timing would be critical, however the formal launch should take place in May / early June 2019, before summer recess.</p>	<p><i>Secretariat</i></p>

	Mr Colin Urquhart thanked Bobath Scotland for hosting the soft launch on the draft action plan and consultation.	
5.	<p>Consideration of the Future Role of NACNC NACNC 29112018 - 05</p> <p>Mr Colin Urquhart noted the need to align the future role of NACNC with the future implementation of the NAP. There was discussion on the extent to which implementation of the NAP would fall to NACNC, and whether the composition of the NACNC was fit for purpose. It is likely that the role of NACNC will change significantly.</p> <p>NACNC discussed whether there is a role for previous sub-groups. Mr Gerard Gahagan thought there was a need for an epilepsy group, however this did not have to report to NACNC. It was suggested there was not the same necessity for sub groups in MS and Parkinson's due to the existence of the Scottish Multiple Sclerosis Register group and Parkinson's Excellence Network. It was agreed that the sub-groups would formally cease.</p> <p>Ms Annie Macleod suggested the biggest issue is accountability for delivery. Ms Kerry Morgan advised that accountability sits with Ministers and Scottish Government.</p> <p>Within the NAP there is a commitment to promote and support the implementation of the HIS General Standards for Neurological Care and Support. There was further discussion on the need to clarify whether NACNC has a role in providing national oversight as governance sits with the organisations providing the care and support.</p> <p>There was some discussion on the timetable for changes to NACNC. It was agreed that the secretariat would circulate a paper by email on possible changes in the new year.</p>	<p><i>All</i></p> <p><i>Secretariat</i></p>
6.	<p>AOCB</p> <p>Mr Colin Urquhart noted that Ms Kirsty Forsyth was stepping down from her role as Project Co-ordinator.</p> <p>Everyone thanked Ms Kirsty Forsyth for the support she had given the committee. Ms Kirsty Forsyth thanked the committee for all their hard work, as it had been a significant milestone to get the plan published.</p>	
DONM	To be advised.	<i>Secretariat</i>