

**NATIONAL ADVISORY COMMITTEE FOR NEUROLOGICAL CONDITIONS
(NACNC)**

MINUTES

3rd May 2019, St Andrew’s House, Edinburgh

Present

Dr Richard Davenport (Chair) (RD)	NHS Lothian
Stephanie Fraser (Deputy Chair) (SF)	Bobath Scotland
Susan Walker (Deputy Chair) (SW)	NHS Greater Glasgow and Clyde
Becky Duff (BD)	Neurological Alliance of Scotland
Gerard Gahagan (GG)	Quarriers
Dr Jenny Preston (JP)	NHS Ayrshire and Arran / IJBs
Dr Callum Duncan (CD)	NHS Grampian
Annie MacLeod (AM)	Parkinson’s UK
Anita Stewart (AS)	Scottish Government
Katie Cuthbertson (KC)	Scottish Government

Apologies

Alison Love	Representative of Service Users
Alison Swierkot	Representative of Service Users
Dr Jonathan O’Riordan	NHS Tayside
Professor Siddharthan Chandran	University of Edinburgh
Dr John Paul Leach	University of Glasgow

1	<p>Welcome, Introductions and Apologies</p> <ul style="list-style-type: none"> RD congratulated GG on his appointment to National Implementation Lead (NIL) for the National Action Plan for Neurological Conditions (start date 3 June). RD also recognised the work that Kirsty Forsyth and Colin Urquhart carried out on behalf of the Committee. <p>Apologies were noted as above.</p>
2	<p>NACNC – Revised Terms of Reference (ToR)</p> <ul style="list-style-type: none"> The Committee considered the revised ToR that reflects changes to its remit following conclusion of work during 2018-19 to publish the draft National Action Plan, and the ongoing role to advise the Scottish Government on its implementation over the next five years. RD thanked everyone for input to date and acknowledged that while some members may decide it is right time to step down, there does need to be some degree of continuity. <p>Consensus that revised membership needs to be leaner and creative about links to wider networks/ groups. Clear message from Action Plan consultation responses is that the neurological community valued the co-production approach adopted in developing the plan and would welcome similar opportunities for input as the Plan is implemented. The Committee reflected on learning from other national committees and groups; these are introducing separate lived experience reference groups that inform policy without placing the burden on one or two individual patient representatives. This has the benefit of engaging</p>

	<p>with more people to hear views and comments from across the neurological community. BD felt an annual public event would also be well received and Neurological Alliance of Scotland (NAoS) would be happy to support organisation of this subject to agreeing resources. AS agreed annual events could be helpful and committed to exploring this.</p> <p>Gaps such as representation on the NACNC from Health and Social Care Partnerships (ask Chief Officers Group to nominate someone on their behalf with a strategic managerial brief) and Regional Planning (strategic manager) were identified.</p> <p>The Committee agreed the NAOs would continue to play a central role in representing third sector organisations on NACNC and felt two reps, both through NAOs, would be the right number to ensure NACNC is still of a manageable size while also ensuring there is sufficient third sector voice. As the Health and Social Care Alliance representative has moved onto a new role, it is timely to explore this group's role under the new remit.</p> <p>The previous condition specific sub-groups to the NACNC have been inactive since work commenced on the National Action Plan in 2018 and in the main have been superseded by independent expert excellence networks. As part of the Plan's Communication Strategy, the NIL will develop links and an interface with these groups/networks.</p>
<p>3</p>	<p>National Action Plan on Neurological Conditions</p> <p>AS provided an update on the National Action Plan. Milestones this year - the consultation report is expected to be published in the Summer, with the final Plan being published in the Autumn.</p> <p>The Committee noted the paper setting out key themes from the consultation responses.</p> <p>AS advised the Committee that health budgets are facing considerable pressure in 2019/20. While the National Action Plan has been identified as a Programme for Government commitment, it will be seeking funding against other priorities such as mental health, integration and waiting times. SW suggested there needs to be clear criteria and transparency around funding proposals.</p> <p>The Committee agreed that when the final Plan is launched, it should be accompanied by what the objectives are in the first year.</p>
<p>4</p>	<p>Scottish Access Collaborative (SAC) – Draft Report on Neurology Specialty</p> <p>The Committee discussed the first draft of the SAC report for neurology that DHI shared with NACNC at an early stage to obtain views ahead of consultation with participants.</p> <p>The report's recommendations will be taken forward in two ways – 1) specialty specific via the Modern Outpatient Programme (Angela Dixon is the</p>

	<p>Improvement Adviser and RD has been asked to be Clinical Lead) and 2) cross cutting specialty themes by SAC projects. AS confirmed the SAC report would be discussed by the SAC Programme Board at its meeting in July (RD to present the report).</p>
5	<p>SAC report implementation – Modern Outpatient Programme/ Waiting Times Improvement Plan</p> <p>KC provided an overview to the Committee about Modern Outpatient implementation, including its focus on pathway re-design/ improvements such as support for GPs on diagnostics, managing patient expectations/ ensuring they receive key information and referral triage/ patient exits/ re-entries.</p> <p>RD commented that he has a meeting with Angela Dixon in May, and AS/GG will meet with AD later in June re synergy with National Action Plan.</p> <p>KC advised there are commonalities across specialities involved in SAC/MOP but also diverse challenges. SAC workshops were first step in process to unpick, identify and target these – learning from progress/ good practice across NHS sector.</p> <p>KC agreed to pass on feedback to DHI that SAC report could be more representative of third sector input at workshops.</p>
6	<p>Healthcare Improvement Scotland</p> <ul style="list-style-type: none"> • General Standards for Neurological Care and Support • Condition specific standards <p>GG and AS updated the committee on a recent discussion with HIS regarding the matter of condition specific neurological standards. The general standards for neurological care were published in March 2019 following extensive engagement and collaboration with the neurological community. These comprehensive and detailed standards now provide a clear framework for patients and organisations about expected care and support that will facilitate consistency in approach within services across Scotland.</p> <p>Organisations across health, social care and the third sector who support people living with neurological conditions will use the standards to demonstrate that they are delivering high quality services.</p> <p>There are five condition specific standards (MS, MND, epilepsy, headaches, Parkinson’s) dating from 2009 that are greatly valued by the respective condition communities; they wish these to be retained and refreshed in line with the general standards. HIS previously gave a commitment to explore this as a next phase of work.</p> <p>In considering what is driving this need and how this might be achieved without the resource associated with a full HIS development team, HIS provided examples of how it has supported other topic areas to produce or refresh</p>

	<p>documents to sit alongside standards. BD highlighted she felt her own organisation would be willing to work with HIS to review the MS standards but it would be crucial that these were then recognised universally in the same way as the general standards. BD agreed to seek views about condition specific standards at the upcoming Neurological Alliance of Scotland Executive meeting.</p> <p>The Committee recognised that implementation of the Standards is a priority and the monitoring of this is not yet established.</p> <p>GG outlined he felt a focus on evaluation and scrutiny with embedded condition specific tools may offer a creative and inclusive method of ensuring implementation of condition specific improvement. AM agreed this sounded as if it would meet needs of her organisation but emphasized BD's point about accreditation of condition specific element.</p> <p>The Committee advised it would be important for transparency around discussions with HIS and other organisations – communications would need to be handled carefully. (ACTION – Once BD has provided update to AS about NAOs views, AS to discuss feedback with HIS and confirm next steps).</p> <p>The Committee recognised that the recruitment and commencement of the NIL post is a vital post for the successful delivery of the National Action Plan but cautioned against the perception that one person will be able to resolve all the challenges ahead.</p>
7	<p>Next steps and summary of agreed actions</p> <ol style="list-style-type: none"> 1) Look at revised terms of reference and feedback to Anita Stewart and Dr Richard Davenport 2) Look at SAC document and feed back to Anita Stewart in the next week. 3) Monitor the development of the the Neurological Standards and inform where appropriate.
8	<p>AOCB</p> <p>AS informed the Committee that the Scottish Government (SG) provided a comprehensive reply to a petition on ME that was lodged with the Public Petitions Committee (PPC) in 2018. In January 2019, the Cabinet Secretary for Health and Sport, and the Chief Medical Officer, also provided evidence to the PPC. At this hearing they gave a commitment to explore the provision of services and different practices for ME across the country, to ensure Scotland is well placed to consider and act on the National Institute for Health and Care Excellence (NICE) updated guideline when it is published later next year. This evidence and SG's written reply can be viewed online at: http://www.parliament.scot/parliamentarybusiness/report.aspx?r=11911&mode=pdf and https://www.parliament.scot/S5_PublicPetitionsCommittee/Submissions%202019/PE1690_Z.pdf.</p> <p>AS has been in discussion with ME third sector organisations, people with ME, the Scottish Health Council, the Scottish Public Health Network and NHS</p>

Education Scotland about options to gather information about the current landscape in Scotland. SG expects to provide an update to the PPC shortly on progress.

Actions from previous NACNC meeting, held on 9th May 2019

NACNC Actions			
No.	Action	For	Update/Status
1	To speak to individual members about their intentions regarding membership of the Group	Chair/ Policy Lead	Completed
2	Consider proposal on reference group and annual event, as part of communications strategy for National Action Plan)	Gerard Gahagan	Ongoing
3	To write on behalf of NACNC to seek nominations	Dr Davenport	Completed
4	As the Health and Social Care Alliance representative has moved onto a new role, it is timely to explore this Group's role under the new remit. This should be followed up with the Alliance (Irene Oldfather)	Chair/ Policy Lead	Completed
5	To formally write to Chairs of sub-groups to close them and record thanks for their contributions	Chair/ Policy Lead	Completed
6	Send comments to AS by 17 May regarding the first draft of the SAC report for neurology that DHI shared	All	Completed
7	Seek views about condition specific standards at the upcoming Neurological Alliance of Scotland Executive meeting	Becky Duff	Completed
8	To discuss feedback with HIS and confirm next steps once Becky Duff has provided update about NAOs views	Anita Stewart	Completed