

NATIONAL ADVISORY COMMITTEE FOR NEUROLOGICAL CONDITIONS

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Title: MINUTES OF THE MEETING HELD ON 03 May 2018

Document Source and Rationale:

This document has been prepared by the Secretariat to provide a permanent record of the committee's discussions, and actions.

Actions Required:

The NACNC is asked to:

- Approve the minute as an accurate record of the meeting.
- Approve the minute of the meeting for publication on the Scottish Government website

Author: The Secretariat

Date: May2018

NATIONAL ADVISORY COMMITTEE FOR NEUROLOGICAL CONDITIONS (NACNC)

MINUTES

3rd May 2018, Bobath Centre, Glasgow

Present

Dr Richard Davenport (Chair)	NHS Lothian
Stephanie Fraser (Deputy Co-chair)	Bobath Scotland
Susan Walker (Deputy Co-chair)	NHS Greater Glasgow and Clyde
Colin Urquhart	Scottish Government
Mike Garden (Item 2)	Scottish Government
Rebecca Duff	Neurological Alliance of Scotland
Gerard Gahagan	Neurological Alliance of Scotland
Alison Love	Representative of Service Users
Dr Craig Heath	Scottish Association of Neurological Sciences (SANS)/NHS Glasgow & Clyde
Dr Jenny Preston	NHS Ayrshire and Arran / IJBs
Gregory Hill O'Conner	The Health and Social Care Alliance
Kirsty Forsyth	Scottish Government, NACNC Project Coordinator
Tanith Muller	Parkinson's UK (On behalf of Annie McLeod)

Attending by Telephone Conference

Dr Callum Duncan	NHS Grampian
Roxie Pankowiak	Policy Manager, Scottish Government

Apologies

Sandra Larkin	NHS Tayside
Claire Ritchie	NHS Lanarkshire
Dr Ed Newman / Dr Craig Heath	Scottish Association of Neurological Sciences (SANS)/NHS Glasgow & Clyde
Dr Jonathan O'Riordan	NHS Tayside
Prof. Siddarthan Chandran	University of Edinburgh
Jane-Marie Stobie	NHS Lanarkshire
Dr John Paul Leach	University of Glasgow/NHS Greater Glasgow & Clyde
Annie McLeod	Parkinson's UK

1.	<p>Welcome, Introductions and Apologies</p> <p>Dr Richard Davenport welcomed Tanith Muller and Gregory Hill O'Conner, to the meeting. He noted that Gregory was replacing Audrey Birt, and recognised the work that Audrey had carried out on behalf of the committee.</p>	
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	<p>Dr Davenport also welcomed Gerard Gahagan in his new role as Acting Chair of the Neurological Alliance of Scotland.</p> <p>Apologies were noted, as above.</p>	
2.	<p>Minutes of Previous Meeting</p> <p>The committee noted that the minutes of the previous meeting held in December 2017, had been formally approved electronically.</p> <p>The secretariat apologised for not recirculating these with the agenda and papers for today's meeting.</p> <p>There were no matters arising.</p>	
3.	<p>ISD Paper: (NACNC 03052018 – 3) NACNC briefing on estimating prevalence of neurological disorders in Scotland from the Scottish Burden of Disease study</p> <p>The committee discussed the contents of the paper. Dr Davenport noted that he had received comments from clinical colleagues in relation to MND and MS numbers. They have suggested that MND prevalence should be restricted to the G12.2 ICD10 code. Dr Davenport will e-mail these to the secretariat to follow-up with ISD.</p> <p>The committee asked if Dr Grant could comment on the possible reasons for under-estimates and over-estimates in the report.</p> <p>Tanith Muller had a number of questions about Parkinson's Disease data. She will e-mail the secretariat separately with these.</p> <p>Stephanie Fraser asked what we are going to do with the information from ISD.</p> <p>Dr Davenport commented that the data is not as complete as we expected, for a number of reasons, and so we should highlight that there may be discrepancies, gaps in uncertainties in the data.</p> <p>Gerard Gahagan suggested that the epilepsy sub-group could look at variance in the data and try to understand it.</p> <p>Stephanie Fraser suggested we needed to try and understand the impact the data or lack of data could have on our ability to plan services, as we may not know who / what</p>	<p><i>Chair</i></p> <p><i>Secretariat</i></p> <p><i>T Muller</i></p>

	<p>needs to plan for. Dr Davenport suggested that data may be worth further work.</p> <p>The committee discussed whether coding could be improved.</p> <p>All agreed the need to have further discussion on why we are gathering data, and what we hope to do with it.</p>	
<p>4.</p>	<p>Lived Experience <i>(NACNC 03052018 – 4)</i></p> <p>Gregory Hill-O'Connor presented the report, noting that it was based on previous focus group work and a review of the literature provided. He asked people to consider how we could develop on the recommendations highlighted by the SLWG for consideration.</p> <p>NACNC discussed whether there were recommendations in the report that were out-with the scope of NACNC, and how best to use the data collected by the survey.</p> <p>There was recognition that the survey was not representative of the entire neurological community, and that some groups may be represented more than others may, however the themes went across all conditions. Tanith Muller cautioned that there was a risk that this work would be seen as a representative audit, when it may not be for all conditions. Alison Love thought the findings were representative of the experience of people with less common conditions.</p> <p>Jenny Preston commented that the findings were very helpful, and were not unexpected. She welcomed the findings on neuro-rehabilitation, and that the report was an accurate representation of the issues experienced.</p> <p>Susan Walker asked what comments were for NACNC, what were for wider government, and what were for inclusion in the National Action Plan.</p> <p>It was agreed that it would be helpful for Gregory Hill-O'Connor to present the main findings at the engagement events.</p> <p>Gregory noted that there were conversations at the SLWG about care pathways and access to specialist services, and suggested considering how we can be proactive at learning from better supported conditions to support pathways for less common conditions.</p> <p>Jenny Preston suggested also considering what we do well,</p>	

	<p>and what we could do better, with a recommendation to learn from what is working well.</p> <p>There was discussion about what could be picked up through the HIS standards work, and recognition of the work done to develop care pathways for older people.</p>	
5.	<p>Mapping Neurological Services in Scotland</p> <p>Susan Walker and Stephanie Fraser gave a verbal progress report. The questionnaire responses had resulted in an extensive report that required time for analysis.</p> <p>Further work, is planned, to analyse the responses.</p>	
6.	<p>Health & Sport Committee Evidence Session on Neurological Conditions 27th March 2018 (NACNC 03052018 6a - Submission from the chair of NACNC) (NACNC 03052018 6b - Official Report) (NACNC 03052018 6c – Letter to Cabinet Secretary)</p> <p>The committee discussed the papers circulated. It was agreed that Dr Davenport would provide a response to correct some of the inaccuracies relating to the NNAG and NACNC comments.</p> <p>Susan Walker noted that the Scottish Government had funded medical and specialist nurse posts, however recruitment had been challenging.</p> <p>It was agreed that it would be helpful to clarify the role of the (NACNC) committee and that the committee does not have a scrutiny role in relation to HIS and the development of standards.</p>	
7.	<p>Update on Neurological Action Plan (NACNC 03052018 7a Literature Search) (NACNC 03052018 7b Engagement Events)</p> <p>The results of the literature search were circulated to the committee. Sophie Ilson, Intern, is reviewing the literature identified to determine what learning can be used in the action plan.</p> <p>NACNC noted that three engagement events are planned in Glasgow, Edinburgh and Aberdeen.</p> <p>Dr Davenport will be joining Scottish Government in July 2018</p>	All

	to work on the Action Plan, for six months.	
8.	<p><u>Items for Information</u> Medical Research – Call for PhD Studentship Applications (NACNC03052018 8a)</p> <p>This item was added to the agenda by the secretariat, to advise novice researchers of funding opportunities.</p> <p>HIS General Standards for Neurological Care and Support Scoping Report (NACNC 03052018 8b)</p> <p>There was discussion on HIS and whether there would be a reference to the new standards in the National Action Plan.</p> <p>Susan Walker noted that HIS are clear their role is not monitoring. Jenny Preston asked whether a mechanism for monitoring outcomes was needed.</p> <p>Tanith Muller suggested learning from the failure of the Long Term Conditions Strategy in England. She suggested that we need a mechanism for developing and recognising improvement, as there is a reputational risk of not delivering this.</p> <p>Jenny Preston shared the HIS view that scrutiny brings compliance not improvement.</p>	
9.	<p>AOCB No items were raised.</p>	
DONM	<p>30 Aug 2018 St Andrew’s House, Edinburgh</p> <p>29 Nov 2018 St Andrew’s House, Edinburgh</p> <p>All meetings 14:00 – 16:00</p>	<i>All to note.</i>