

NATIONAL ADVISORY COMMITTEE FOR NEUROLOGICAL CONDITIONS (NACNC)

MINUTES 7th December 2017, Edinburgh

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
Alison Swierkot	Representative of Service Users
Dr Craig Heath	Scottish Association of Neurological Sciences (SANS)/NHS Glasgow & Clyde
Dr Jenny Preston	NHS Ayrshire and Arran / IJBs

Audrey Birt	The Health and Social Care Alliance
Kirsty Forsyth	Scottish Government, NACNC Project Coordinator

Apologies

Sandra Larkin	NHS Tayside
Dr Callum Duncan	NHS Grampian
Ian Grant	NHS ISD
Claire Ritchie	NHS Lanarkshire
Dr Ed Newman	Scottish Association of Neurological Sciences (SANS)/NHS Glasgow & Clyde
Dr Jonathan O'Riordan	NHS Tayside
Prof. Siddharthan Chandran	University of Edinburgh
Jane-Marie Stobie	NHS Lanarkshire
Dr John Paul Leach	University of Glasgow/NHS Greater Glasgow & Clyde

In Attendance for Item 2

Aileen Campbell, MSP	Minister for Public Health & Sport
Craig Keddie	Private Secretary, Minister for Public Health & Sport

1.	Welcome, Introductions and Apologies Dr Richard Davenport, Chair, welcomed everyone to the meeting. Apologies were noted, as above.	
2.	Minister for Public Health & Sport	

The Minister for Public Health & Sport, Aileen Campbell, MSP attended the meeting.

As Ms Campbell was unavoidably detained in Parliament, Dr Davenport continued discussion on items 3, 7 and 8; and returned to this item on her arrival.

Dr Davenport welcomed Ms Campbell, Mike Garden and Craig Keddie to the meeting, noting that neurological conditions are part of Ms Campbell's public health remit, and that a number of people had questions. Dr Davenport thought this was an opportunity to share the committee's Vision (NACNC 31082017 – 05) and explained that the Vision and announcement of an Action Plan had provided an opportunity to refocus.

Dr Davenport noted that the committee had an advisory remit, and did not have a lot of data, and so had decided to do something about this lack; and then the Neurological Action Plan came into being. He observed that there is a temptation and nervousness that we will focus on acute health and not enough on community, and explained that it is difficult to measure everything we need to. Once we do this and have an action plan we need to think about how best to implement actions and resources to support change.

Ms Campbell said she was very proud and privileged to be the Minister for neurological conditions. She explained that there is a lot of political interest around neurological conditions and need for national coherence around issues to try to focus minds, gather expertise and knowledge, and bring together a plan about how we support people and their carers. Ms Campbell noted that the committee was finding out about peoples experiences, good and bad, and mapping what we have. She asked for a plan that improves services.

The Minister also welcomed the opportunity that the carers legislation offered, and she asked the committee to consider how we make the most of this.

She then concluded by assuring the committee that she believes this work can be insightful, and have impact, and invited the committee to share their thoughts on improvement.

Dr Davenport asked The Minister if there was a rough timetable. Ms Campbell replied that the action plan was an attempt to try and have a set of actions that are deliverable. She thought there had to be a bit of pace, and wants to keep momentum going, but keep it manageable and workable.

Dr Davenport invited Ms A Birt to comment. Ms Birt explained that she is working on the Alliance Neurological Programme, and believes it has a real potential to make a difference. She also wanted pace, however thought it may well be hard to complete the lived experience work and patient engagement by end of March. Focus groups have commenced, however, there is a challenge in contacting people with rare conditions.

Ms Birt described some of the main themes and issues that have come up in the work so far:

- Community Support, including access to physiotherapy and other specialist AHP services, including but not necessarily specialist nurses
- Loneliness and Social Isolation, how do we support people and carers in the community?
- Communication, how people join up the services staff to staff, and staff to people with lived experience.

Ms A Swierkot described the experience of being told by a member of staff that the NHS does not have the resources or experience to treat her.

Ms S Fraser noted that Ms Swierkot's experience straddles Health & Social Care. Integrated Joint Boards (IJBs) are at an emerging stage of development, it is vital to engage with IJBs. Ms Fraser noted that this is much broader and more complex and asked how do we best influence IJBs.

Ms Campbell believes that integration is the right approach. She described the example of transition issues and advised the committee of recent support provided through the ILF (Independent Living Fund) to look at transition.

Ms Birt suggested better support for self management, education from specialists to staff in A&E and other staff, and that integration is an opportunity to look at re-enablement, and so we need to get neurological conditions up the agenda.

Ms Campbell commented that in the experience of her constituents, the support they get is not necessarily what people are looking for, there is also a rurality dimension to this, and we need to give communities more credit for being resilient.

Ms Swierkot said some local resources are being closed, on the basis of more support for self management, and centre users are protesting about cuts.

<p>Ms Campbell recognised that self management needs a balanced approach.</p> <p>Dr Davenport acknowledged that communication came across as a big issue.</p> <p>Mr G Gahagan asked The Minister for her view on the traditional model of healthcare and developing a truly integrated model. He asked how do we support and secure resources for the voluntary sector and IJBs.</p> <p>Ms Campbell said that if we have the audience, and the data, then we have more evidence to push this up the agenda. She referred to the work of Bobath Scotland and West Dunbartonshire Health and Social Care Partnership, that improved knowledge without being large scale.</p> <p>Ms Fraser noted that we also need people with the skills and knowledge to deliver change.</p> <p>Ms Campbell agreed that information will help strengthen the case for discussion with IJBs about what they need to do, and if there are opportunities then Government will take them.</p> <p>Ms Duff suggested that third sector has a voice and a responsibility to be taking information forward, as the third sector is good at influencing the wider landscape.</p> <p>Ms Birt suggested that Neurological Voices need to be part of the voices speaking to IJBs.</p> <p>Ms Duff commented that the Third Sector does not want to be restrained with regards to use of the data collected, that a pathway approach could be useful, that the House of Care Model could be used, and that mapping will help identify where resources are.</p> <p>Ms Campbell noted the example of the HD Network, and commented that there will not be able to be specialists for all conditions in all areas so we need to pull this together.</p> <p>At the mention of specialists, Dr Davenport introduced Dr Heath.</p> <p>Dr Heath reported that members of the Scottish Association of Neurosciences (SANs) had raised concerns about the provision of acute neurology, shortage of neurology beds, and the neurology and neurophysiology workforce. He commented that there were two issues that would not be addressed by mapping; the increased use of locums, and 9 +</p>	
---	--

	<p>1 contracts. Ms Walker noted that recruitment issues also exist, as vacant posts are unable to be filled.</p> <p>Ms Campbell suggested it would be useful to get Dr Heath's thoughts on the best way to increase the workforce, as all agreed it was better to invest in posts, rather than short-term agencies.</p> <p>Ms Walker hoped to get examples of best practice, and would like information on how we can improve services in the absence of neurologists.</p> <p>Ms Campbell said there had been an issue recruiting to GP training, that has been addressed, and that perhaps this issue can also be unblocked. Dr Davenport noted that neurology trainee posts are filled, so the issue is perhaps the number of trainees.</p> <p>Ms Fraser asked the Minister for her views on 'What does an action plan look like?'</p> <p>Ms Campbell suggested it was a shorter process to develop; a list of things to do; a way to implement them, and a way to make them happen.</p> <p>Ms Campbell concluded by saying we want to bring the plan together, and feel confident that we are improving support for people with neurological conditions, and to keep the momentum going.</p> <p>Dr Davenport and the members of the committee thanked Ms Campbell for her participation and encouragement.</p>	
3.	<p>Minutes of Previous Meeting and Matters Arising</p> <p>The minutes contained in paper <i>NACNC 07122017-02</i> were approved as an accurate record of the meeting, and approved for publication.</p> <p>There were no matters arising.</p>	<i>Secretariat</i>
4.	<p>Mapping Neurological Services in Scotland December 2017</p> <p>Dr Davenport acknowledged work carried out by sub-groups, and thanked Stephanie Fraser and Susan Walker for their work in developing this into the Service Mapping Questionnaire. (<i>NACNC 07122017 – 04</i>).</p> <p>Dr Craig Heath suggested amending the wording of Question 6, regarding the frequency of neurology services on-site.</p> <p>Dr Jenny Preston asked for the Allied Health Professionals /</p>	

	<p>Health Care Scientists (AHP/HCS) workforce profiles in Questions 37 and 40 to be amended to capture information on the number of staff working as Consultants or in Advanced Practice.</p> <p>It was agreed both would send their suggestions to the secretariat, following the meeting.</p> <p>The secretariat would incorporate revised wording after review by the Deputy Co-chairs.</p> <p>Ms Fraser described the proposed distribution of the questionnaire to Health Boards, Integrated Joint Boards and Third Sector. It was noted that each organisation was being asked to submit a single co-ordinated return, although a suggested distribution was enclosed in the covering letter.</p> <p>It was agreed to run the survey questionnaire until late January 2018, with a reminder to organisations mid January.</p>	<p><i>Dr Heath / Dr Preston</i></p> <p><i>Deputy Co-chairs / Secretariat</i></p>
<p>5.</p>	<p>Neurological Analytical Programme</p> <p>The committee noted that Dr Ian Grant, Principal Researcher, NHS ISD had given his apologies to the committee due to ill health.</p> <p>The committee noted the presentation circulated on his behalf and agreed to defer this item to a further meeting.</p> <p>The secretariat offered to arrange a video conference call for clinicians on the Research & Audit group to review prevalence. It was agreed this could be helpful.</p>	<p><i>Secretariat</i></p>
<p>6.</p>	<p>Lived Experience Work-stream</p> <p>Dr Davenport referred to the comments made earlier in the meeting by A Birt, and opened up this item for discussion.</p> <p>A number of points were raised:</p> <ul style="list-style-type: none"> • The documents referred to in the report are to be referenced. A Birt agreed to re-issue with the references identified. • The themes in the paper are not in order of importance • Specialist Nurse Support was not identified as a theme, this was surprising to some committee members • Improved community support is included – which is the key point of contact for people living with rarer conditions. • What lies behind peoples expectations of community 	<p><i>A Birt</i></p>

	<p>rehabilitation services? There are different definitions of rehabilitation, as well as a move to normalise disability</p> <ul style="list-style-type: none"> • Care co-ordination is considered very important. • Support for Carers has been raised • Communication is a very important issue, between people and staff, and between professionals and agencies • Presenting at A&E, and knowing when symptoms are due to a person's neurological condition or something else • Access to technology, including phone advice for carers • Peer support and Self-management, and the need for a directory of services <p>There was also discussion on where this work sits within the project plan, and the timing for this work-stream.</p> <p>Mr Urquhart noted that IJBs already have a set of priorities that has been mandated, neurological conditions are not on the list as a separate item so we need to consider this further in order to influence IJBs and prepare them in delivering our priorities identified in the action plan.</p> <p>A Birt thought it is important to keep the pace that is developing with this work, and hopes to distribute a survey for people living with neurological conditions by the end of January 2018, with responses due by Mid – February. She asked for assistance from committee members in getting this distributed to as many respondents as possible.</p>	
6.	<p>Items for Information HIS Neurological Standards</p> <p>It was noted that Healthcare Improvement Scotland (HIS) have appointed a Project Manager to take forward the development of the General Neurological Standards.</p> <p>Ms Duff commented that Maureen Watt, MSP, during a debate in Parliament, had announced that the standards are now being incorporated as part of the Neurological Action Plan. Ms Duff sought clarification on this.</p> <p>Mr Urquhart confirmed that our longer term ambition is to develop a programme of monitoring, governance and quality improvement – to which the standards would be central. Mr Urquhart thought this would be the next step after the action</p>	All

	plan and there would be plenty of opportunities to discuss this over the coming months.	
7	Neurophysiology Dr Davenport reported that the planned meeting has taken place. A report of the meeting is due to be sent to participants shortly. This will include recommendations for consideration by Regional Planning Directors and Boards.	
8.	AOCB No items were raised.	
DONM	8 Feb 2018 <u>NOTE:</u> Meeting Cancelled. Meeting with ISD arranged. 10 May 2018 St Andrew's House, Edinburgh 30 Aug 2018 St Andrew's House, Edinburgh 29 Nov 2018 St Andrew's House, Edinburgh All meetings 14:00 – 16:00	<i>All to note.</i>