



Cynghrair Niwrolegol Cymru
Wales Neurological Alliance

Minutes of Cross-Party Group Neurological Conditions meeting on

Tuesday 18th February 2014

Committee Room 4, Tŷ Hywel, National Assembly for Wales

Present

Cardiff

Mark Isherwood AM (Chair)
Aled Roberts AM
Andrew R T Davies AM
Kirsty Williams AM
Christine Chapman AM
Darren Millar AM
Margaret Ware, Myotonic Dystrophy Support Group
Helen Payne, Hywel Dda UHB
Mary Carter, CMT UK
Steve Walford, Ataxia South Wales
Alan Thomas, Wales Neurological Alliance and Ataxia South Wales
Graham Findlay, Dystonia Society
John Meredith, Dystonia Society
Ana Palazon, Wales Neurological Alliance and Stroke Association
Paul King, CEO Dystonia Society
Joseph Carter, Wales Neurological Alliance and MS Society
Jamie Matthews, MS Society
Pip Ford, Chartered Society of Physiotherapy
Dr Chris Jones, Deputy Chief Medical Officer, Welsh Government
Caroline Lewis, Policy Manager, Major Health Conditions Policy Team
Rob Thomas, UCB Pharma
Ffion Haf, Meningitis Now
Sarah Bell, The Brain Injury Rehab Trust
Mirriam Dupree, Cauda Equina Syndrome Association
David Murray, Wales Neurological Alliance and The Cure Parkinsons Trust
Dr Malin Falck, Clinical Psychologist, Cwm Taf UHB
Dr Tanya Edmonds, Clinical Neuropsychologist, ABMU HB Regional Service
Michelle Herbert, The Brain Tumour Charity
Dr Claire Willson, Clinical Neuropsychologist, Cardiff and Vales UHB
Ann Sivapatham, Wales Neurological Alliance and Epilepsy Action Cymru

Nathan Sivapatham, Epilepsy Action Cymru
Maggie Hayes, Wales Neurological Alliance
Dr Kathryn Peall, UHW neuro service/medical adviser to Dystonia Society
Barbara Locke, Parkinsons Society
Rachel Williams, Parkinsons Society

Wrexham link

Annette Morris, Director of the North Wales Neurosciences Network, Betsi Cadwaladr University Health Board
Dr John Hindle, Clinical Lead North Wales Neuroscience Network, Betsi Cadwaladr, University Health Board
Karen Shepherd – Patient Representative, North Wales Neuroscience Network Board
Urtha Felda, Wales Neurological Alliance and MS Society Cymru and WNA rep on the North Wales Neurosciences Network

Apologies

Simon Thomas AM
Bethan Jenkins AM
Kevin Thomas, Wales Neurological Alliance and Motor Neurone Disease Association and WNA rep on the North Wales Neurosciences Network
Dr Claire Hirst – Consultant Neurologist, Hywel Dda
Michelle Price – Physiotherapist, Powys Local Health Board
Laura Edwards – Parkinsons Disease Nurse Specialist
Dr Owen Pearson – Consultant Neurologist – ABMU
Nia Came - Lead Speech and Language Therapist, Cardiff and Vale
Kate Steele– Wales Neurological Alliance and Shiny Cymru
Jenny Reynolds - Specialist Care Adviser North and North- Wales
Prof Matt Makin – Chair of the North Wales Neurosciences Network and Executive Medical Director and Director of Clinical Services, Betsi Cadwaladr University Health Board
Dr Rhys Davies, Consultant Neurologist, The Walton Centre Foundation Trust (North Wales Neurosciences Network)
Catriona Fearne - OT Clinical Specialist for MS in North Wales
Leigh Campbell - Specialist Physiotherapist in Neurology in North Wales
Robin Moulster, BASW Cymru

Mark Isherwood AM (Chair) thanked the IT technicians for making it possible for colleagues in Wrexham to take part in the meeting. Ana Palazon (Chair of the Wales Neurological Alliance) welcomed attendees and thanked colleagues from the Welsh Government for their attendance at the meeting. Ana provided a brief overview of the Wales Neurological Alliance (see www.walesneurologicalalliance.org.uk).

Minutes of the last meeting and matters arising

Accuracy – Ana Palazon missing from attendees.

Minutes recorded as true and accurate account of the meeting.

Inquiry into access to neurophysiotherapy - 12 months review

Pip Ford of The Chartered Society of Physiotherapy provided feedback on the work that has been carried out by local health boards. See summary report provided.

Maggie Hayes of Wales Neurological Alliance (WNA) outlined that the WNA has produced a summary report of all the feedback from meetings attended by Executive Committee members of the WNA and also written updates received from the LHBs. See report provided. Maggie explained that the draft Delivery Plan picks up some of the issues but does not respond to some of the more detailed recommendations in the report. The WNA would still like the Welsh Government to take forward recommendation 7, 8 and 12 as a specific piece of work. The WNA would like Mark Isherwood AM to write to the Minister for Health and Social Services to request that the Welsh Government sponsor a piece of work that builds on the knowledge already held by Health Boards to determine, how to better utilise these facilities to improve the lives of people living with neurological conditions and indeed anyone seeking to access physiotherapy.

Dr Jones commented that he is supportive of self referral to physio should reduce waiting list times and is cost effective.

Discussion was had regarding the level of responses received. Concern was raised that there was no response from Therapies in Betsi Cadwaladr. It was confirmed that no response has been received to a written request for an update and that discussion with Heads of Therapies had advised that the Health Board felt they were meeting the recommendations already. It was generally felt that it would have been helpful to have received more information from the Head of Therapies in BCU.

Action: Dr John Higgins advised that he will take forward the feedback regarding no response from Betsi Cadwaladr Health Board. Pip Ford to liaise with Ian Mitchell, Clinical Director of Therapies at BCU to ask for a response to the request for an update.

Action: Mark Isherwood AM to write to the Minister to request information on what actions will be taken in relation to the specific recommendations 1, 7, 8 and 12.

Delivery Plan for Neurological Conditions

Dr Chris Jones (Deputy Chief Medical Officer) and Caroline Lewis (Policy Manager, Welsh Government) updated the group on the work they have been doing in relation to the Delivery Plan for Neurological Conditions. Dr Jones thanked the WNA for their contribution to the development of the plan.

Caroline advised that the delivery plan is framed in 6 key delivery themes, and can be cross- referenced to other plans. Dr Jones advised that he recommends that the delivery plan is read in conjunction with other delivery plans such as the Rare Diseases plan, Respiratory and End of Life plans. Dr Jones stated that delivery plans are designed to provide purpose to population planning and intended to make LHBs accountable. Examples of accountability include annual updates of progress by all Local Health Boards. Establishment of plans should put in place a system that will result in improvement that is measured and has an outcomes framework.

Caroline Lewis updated the meeting that the consultation for the delivery plan is now closed. They have received 72 responses; the majority of responses have been from patient groups, professional advisory groups and impairment specific organisations. They have received 3 replies from individuals. Caroline advised that she anticipates that there will be another month of analysis and that it is hoped that the plan will be published by the Minister in April or May 2014. Caroline took on board feedback provided by attendees that Paediatrics and Carers are not strong enough in the plan.

Jamie Matthews of the MS Society outlined the WNA response to the plan (see report attached to email). He advised that there was concern that the aims of the plan are aspirational and that there is a potential conflict in relation to LHBs accountability for delivering the themes.

Two key areas of concern are Assurance and Timescales. Jamie advised that it is felt that there is too much reliance on the complaints process and that more robust measures are needed. He also expressed concern that timescales were not realistic and that some deadlines had already been missed.

Dr Jones advised that resources are scarce and that there is no additional funding but that there is a significant amount of resource being used in Wales. He feels that good quality care can cost less. He advised that there is no national neurological outcomes measure and that he would appreciate any support that could be provided to assist him with developing this area.

Discussion took place on how the Cancer Networks in North Wales have helped implement the Cancer Plan. The excellent work that is being undertaken by the North Wales Neurosciences Network in Betsi Cadwaladr HB was highlighted and its success acknowledged and it was felt that the North Wales Neurosciences Network would be essential in leading, driving and implementing the new delivery plan. It was noted that clinical networks are currently being reviewed across Wales.

Discussion regarding the role of specialists versus generalist clinicians. Dr Jones advised that there is a shift towards generalist clinicians where they support people with multiple conditions. He felt that specialist focus can make some care fragmented. Ana Palazon advised that she felt strongly that there is a definite need for a specialist in neurological conditions. Dr Hindle advised that he is a Specialist in Parkinsons and sees all ages of people. He advised that care of elderly positions should have expertise that is appropriate and that the baseline work for the implementation group of the plan should include generalists. Mary Carter (CMT UK) stated as a patient, she does not mind whether she is seen by a specialist or generalist as long as they understand her condition. She raised concern about Quality of Life indicators and that her lived experience of her condition is often deemed as anecdotal and is discounted. Dr Jones talked about the Prudence Health Care strategy which focuses on people making decisions with their clinicians.

Kirsty Williams AM asked for clarification on what the consequences are for LHBs that do not deliver on the plan themes. Dr Jones advised that each LHB will have to

evidence their progress on an annual basis and that this will form part of their key performance indicators.

Dr Jones advised that the implementation group would conduct a baseline assessment. Darren Millar AM advised that he was disappointed that the baseline work has not already been done and that he feels a baseline should have been the starting place for the development of the plan. Caroline Lewis advised that the baseline for the delivery plan has been taken from the 2008/9 neurosciences review and that the Welsh Government has built its understanding from this. The implementation group will carry out a more detailed assessment. Furthermore, the plan incorporates 540 + recommendations from various reports (including the CPG Neurological Conditions A&E and Neuro Physio reports) and therefore, they feel they have a good understanding of the gaps.

David Murray advised that he feels it is critical that people are asked what they want from services and who they want treatment from. Dr Jones advised that he is keen to develop engagement with citizens. Annette Morris advised that the North Wales Neuroscience Network was in the process of setting up a Service User Forum Group in North Wales. The Network has also set up Disease Specific Advisory Groups (DSAGs) on MS, Epilepsy and Motor Neurone Disease and is in the process of setting up a Disease Specific Advisory Group for Movement Disorders.

Discussion was held in relation to more joined up working, in particular with local authorities. It was felt that this is a significant gap of the plan. Caroline and Dr Jones advised that they would take this on board. Annette Morris highlighted that Local Authorities are key members of the Neurosciences Network Board in North Wales.

Alan Thomas asked who will chair the implementation group – Dr Jones advised that this would be for the LHB Chief Executives to decide.

Action: Mark Isherwood AM to write to the Minister to highlight concerns that:

- The plan is mainly aspiration due to the absence of new and dedicated resources, more detailed action plans and robust measurement, together with the mechanisms for sharing and replicating best practice.
- There is a need to clarify accountability of LHBs to deliver the plan
- The plan requires specific recommendations in relation to children
- Whilst some health conditions are a consequence of health inequalities, some neurological conditions are not linked to health inequalities, e.g. they are genetic or a result of trauma.
- The plan needs to present a clearer understanding of the current baseline of health services for people with neurological conditions. A baseline assessment of current services would identify where money is currently being used across services and possibly identify points of possible transfer of finance without increasing costs. Annette Morris highlighted that NCS, Neurological Commissioning Support, had given a presentation on their work to the North Wales Neurosciences Network Board. They could be asked to support Wales in this regard.

- The plan should have a distinct 'Carers needs' theme to recognise and support the role of carers for people with neurological conditions.

Dystonia Society – barriers faced by people living with Dystonia in Wales

Paul King, CEO of Dystonia Society gave a presentation on the issues experienced by people living with Dystonia – see PowerPoint on email.

There are some key issues in Wales, for example in Swansea where Botox clinics operate on a one out, one in system. This model is not supportive of long term conditions such as Dystonia.

The Dystonia Society advised that it finds it difficult to engage as much as they would like in Wales. They are keen to link up further with networks such as the Wales Neurological Alliance (which they are members of).

Christine Chapman AM thanked the Cross Party Group and the Dystonia Society for their presentation. She expressed that she was keen to introduce the Dystonia Society so that it could be part of the wider group.

John Meredith advised that he was keen to see a better awareness of the condition with GPs. He recalled that his own experience of getting funding for treatment had taken 4 years. Dr Jones expressed that he was sorry to hear of this difficulty and that he is particularly keen to link with the Dystonia Society to discuss the issues raised in particular the issue in Swansea with Botox Clinics.

Dr Peall advised that early intervention is better in the long term and is more cost effective. Some of the education in relation to older GPs could be that until the 80s Dystonia was considered a psychological condition. The threshold for treatment referral is dropping.

Dr Hindle confirmed that they see people in North Wales in Movement Clinics and that Specialist Care of the elderly teams offer Botox. Annette Morris emphasised that she would be pleased to see the Dystonia Society play an active role in the Disease Specific Advisory group (DSAG) for Movement Disorders in North Wales.

AOB – no items raised.

Future meeting dates:

- Tuesday 25th June 2014
- Tuesday 16th September 2014 (CPG AGM)

END.