



Cynghrair Niwrolegol Cymru
Wales Neurological Alliance



Cynulliad Cenedlaethol Cymru
National Assembly for Wales

Minutes of the Cross-Party Group for Neurological Conditions

Friday 14 November 2014

Oriel Country Hotel, Upper Denbigh Rd, St Asaph, Denbighshire LL17 0LW

Present: There were 81 people present at the meeting including professionals, people living with neurological conditions and their carers, and representatives from the voluntary sector. Attendees who were formal members of the Cross-Party Group or speakers included:

Mark Isherwood AM (Chair) - Welsh Conservatives
Aled Roberts AM – Welsh Liberal Democrats
Kevin Thomas – WNA and MNDA
Joseph Carter – WNA and MS Society Cymru
Urtha Felda – WNA and MS Society Cymru
Barbara Locke – WNA and Parkinson's UK
David Murray – Cure Parkinson's Trust
Professor Matthew Makin - Medical Director, Betsi Cadwaladr University Health Board
Annette Morris – Director of the Neuroscience Network
Dr Peter Enevoldson – Medical Director, The Walton Centre
Dr John Hindle – Llandudno General Hospital

Apologies: **Keith Davies AM – Welsh Labour**
Janet Finch-Saunders AM – Welsh Conservatives
John Griffiths AM – Welsh Labour
Lesley Griffiths AM - Welsh Labour
Llyr Huws Gruffydd AM – Plaid Cymru
Rhun Ap Iorwerth AM – Plaid Cymru
Alun Fred Jones AM – Plaid Cymru
Ann Jones AM – Welsh Labour
Elin Jones AM – Plaid Cymru
Sandy Mewies AM - Welsh Labour
Darren Millar AM – Welsh Conservatives
William Powell AM – Welsh Liberal Democrats
Antoinette Sandbach AM – Welsh Conservatives
Carl Sargeant AM – Welsh Labour
Ken Skates AM – Welsh Labour

(**bold** names denote registered members of the Cross Party Group who sent their apologies)

1. Introductions and apologies

Mark Isherwood AM welcomed everyone to the Oriel Country Hotel and talked them through the fire exit procedures.

2. Background and introduction to the Neurological Conditions Delivery Plan (from voluntary sector perspective)

Kevin Thomas gave an introduction to the Wales Neurological Alliance and gave a service user perspective on the Neurological Conditions Delivery Plan.

The Delivery Plan is focussed on 7 themes:

- Raising awareness of neurological conditions.
- Timely diagnosis of neurological conditions.
- Fast and effective care.
- Living with a neurological condition.
- Children and young people.
- Improving information.
- Targeting research

Kevin explained how the Wales Neurological Alliance had worked with the Welsh Government as they drafted the plans and had pushed for stronger performance measures.

The Delivery Plan will be overseen by the All Wales Neurological Implementation Group chaired by Betsi Cadwaladr UHB Medical Director, Professor Matthew Makin and Chair of the North Wales Neurosciences Network. There are three voluntary sector places, so that the voice of the service user is represented.

The role of neurological condition organisations needs to be to:

- Ensure two way communications from local to national.
- Ensure communication between people living with a neurological condition and the WNA Executive Committee.
- Highlight geographical inequities
- Campaign.

3. Overview of the North Wales Neurosciences Network and the how the Network work plan fits with the Delivery Plan in North Wales

Annette Morris gave an overview of the North Wales Neuroscience Network.

In April 2012 the North Wales Neurosciences Network was formally established. It is a professional association of statutory and non-statutory bodies who input into the delivery of services for patients with neurological conditions in North Wales. Network Board members include the NHS, patient and carer representatives, the Community Health Council, the Voluntary Sector, Social Services, Welsh Ambulance NHS Trust, The Walton Centre NHS Foundation Trust, Bangor University, Wales Neurological Alliance, Public Health Wales, North Wales Hospices, North Wales Local Government, Welsh Health Specialised Services Committee (WHSSC), North Wales Critical Care Network and the North Wales Stroke Forum. The Network also works closely with Clatterbridge Hospital, Countess of Chester Hospital, Robert Jones Agnes Hunt Hospital in Gobowen, Salford Royal NHS Foundation Trust and University Hospital of North Staffordshire. The Network covers all services for adults and children with neurological conditions.

The Network is working closely with the Policy Leads for Neurosciences in Welsh Government and the All Wales Cross Party Group for Neurological Conditions, and it has strong service user and Third Sector input through the Wales Neurological Alliance.

Annette explained that the Network is clinically led and has adopted a whole system, partnership approach to the planning, commissioning and delivery of Neurological

Services for the North Wales population. The Network Board has determined a programme of work and priorities, recognising that not everything can be delivered at the same time. Annette outlined the current key work streams of the Network.

The Welsh Government expects Local Health Boards directly, and through the Welsh Health Specialised Services Committee (WHSSC), to commission and deliver neurological services to their population commensurate with assessed need. The Network Board ensures that the direction taken in the delivery and development of neurosciences services by BCUHB is in the interests of the population, is in line with policy requirements and national guidance and is evidenced based. The Neurosciences Network will review the needs assessment and understand the needs of the population for neurological services, and will advise on the necessary steps in the future to close the service gap.

Annette explained how the Network had adapted in response to the Delivery Plan and demonstrated how they were working through each of the 7 themes.

She explained how Disease Specific Advisory Groups (DSAGs) had been established for Epilepsy, MND, MS, and Movement Disorders, with others being developed. DSAGs bring together a multi-disciplinary team of professionals with service user representatives and are developing practical solutions to condition-specific problems. These groups have a number of key conferences planned to raise awareness of neurological conditions.

Annette talked about the new Neurosciences Network Medicines Management Group that had recently been established and talked about its role working with the DSAGs. This group will focus on new drugs coming on line, efficacy and drug protocols etc. The Network is constantly aiming to share good practice to deliver improved health and wellbeing outcomes for patients.

Annette talked about the Network Academic, Education and Information Group. The remit of this group is to link clinical practice with Academia and research, and to improve the education, knowledge and management of neurological conditions. This group has a number of key conferences planned to raise awareness of neurological conditions and the research agenda. This group has also been set up to Drive service transformation and lead the Dignity and Respect agenda, Empowering Service Users agenda and to lead on the Self Management agenda. Membership includes Health, Third Sector, LA, Consultants from Tertiary Centres, Chair of the DSAGS.

Finally Annette and Kevin Thomas talked about their hopes to establish a Network Neurological Conditions Service User Forum if funding can be accessed to ensure that the service user voice is heard.

4. Update from the Walton Centre

Dr Peter Enevoldson, Medical Director of the Walton Centre introduced himself and his organisation. The Walton Centre is based in Merseyside and is the nearest Tertiary Centre to North Wales. It is a Foundation Trust and has governing body of 17 members (3 from North Wales), due to people living in North Wales representing a considerable group of their clients.

The Walton Centre welcomes the Neurological Conditions Delivery Plan and sees it as a way of better integrating primary, secondary and tertiary services. He felt that the timescales were very ambitious and that it would take 10 years and a significant investment to deliver.

Dr Enevoldson told the CPG that the Walton Centre is in a period of expansion. It has grown by 25-30% in the last 5 years and 100,000 outpatients were seen last year. There are 4 MRI scanners and they have been developing satellite clinics across North Wales

(Bangor, Rhyl and Wrexham) and the North West of England – 32 sites in total. A new rehabilitation centre is opening in January 2015 and they are trialling telemedicine to Bangor and Isle of Mann.

5. Questions from the floor

Mark Isherwood AM invited the audience to ask questions about the Neurological Conditions Delivery Plan or any other issue.

a. How will the Implementation Group monitor progress? How will they hold health boards to account?

The All Wales Implementation Group will hold health boards to account at their quarterly meetings. Civil servants sit on the group, the chair will give a quarterly update to the Welsh Government and there will be a full annual report tracking progress of the health boards.

b. How will carers be supported and how will services be affected in rural areas? The questioners were keen to understand how the plan would be implemented in rural areas such as Meirionydd and southern Conwy which are a long way from District General Hospitals.

Professor Makin argued that the Delivery Plan shouldn't operate in isolation and that the Health Board needs to look at how all services reach into the rural hinterland. 'North Wales is not a large city' he said. Services need to be redesigned so that people can be supported as close to home as possible.

Dr Hindle suggested that the Powys and Betsi Cadwaladr UHB delivery plans need to be aligned so that people don't fall through the cracks. The role of carers is recognised in all delivery plans and at a local and national level, organisations need to think about how this will happen.

Mark Isherwood AM and Kevin Thomas suggested that co-production was needed and that the expertise in the CPG in St Asaph needs to be harnessed to design appropriate services.

c. How do we prevent conditions in the first place and how will the delivery plan affect people's real lives?

The Neurological Conditions Delivery Plan has short, medium and long term objectives so there are changes that will come into effect relatively quickly and impact on people's lives.

Theme 7 of the plan is Targeting Research, so there is a commitment by Welsh Government and the Health Boards to encourage service users and clinicians to take part in research trials developing new medical treatments that could alleviate symptoms now or possibly lead to long term improvements.

Annette Morris confirmed that Betsi Cadwaladr UHB Neurosciences Network is investing in education and training to improve understanding on neurological conditions.

d. How do the rehabilitation services in North Wales link into the work of the Neuro Therapy Centre in Saltney or with other voluntary sector groups?

Annette Morris spoke about the existing service level agreement with the Saltney Centre and expressed a desire to potentially work with other voluntary sector partners to link into their services.

e. What is the Health Board doing to improve access to physiotherapy services?

Mark Isherwood AM spoke about the Cross-Party Group's inquiry into physiotherapy services and how elements of this were now being taken forward by the Welsh Government.

Professor Makin argued that services need to be redesigned so that physiotherapy and other rehabilitation services could be accessed in the community.

f. Why can community hospitals be better utilised? An example was given of a DGH which had disposed of old gym equipment during a re-fit rather than passing it on to a community hospital.

The panel were not able to comment on the specific example, but it seemed to re-inforce Professor Makin's earlier suggestion that services across North Wales needed to be reviewed.

g. The final question concerned an individual whose husband is living with a progressive form of MS, who had had a bad experience with the health board and social services. She had had a positive experience with the palliative care team, but prior to this service had been poor.

Professor Makin agreed to look into the case but suggested that this was an example of why services needed to be multi-disciplinary, so that professionals 'could get one step ahead of the condition', rather than reacting too late. He spoke about the need of staff to be professional and courteous and gave the example of the 'hello my name is' scheme – new training to teach staff how to treat patients and carers.

6. Next steps and close of meeting

Mark Isherwood AM thanked everyone for coming and explained that the minutes would be typed up and circulated to the local neurological alliances.

The next meeting of the Cross-Party Group for Neurological Conditions will be Tuesday 10 February 2015 – Committee Room 4, National Assembly for Wales.