



Cynghrair Niwrolegol Cymru Wales Neurological Alliance

Minutes of Cross-Party Group Neurological Conditions meeting on

Tuesday 24th March 2015

Committee Room 4, Tŷ Hywel, National Assembly for Wales

Via VC to Wrexham Maelor Hospital

Present

Cardiff

Mark Isherwood AM (Chair)
Aled Roberts AM
Pip Ford, Chartered Society of Physiotherapy
Lynne Hughes, WNA and MS Society Cymru
Robin Moulster, BASW Cymru
Ana Palazon, WNA and Stroke Association
Cath Taffurelli, BASW Cymru
David Murray, WNA and Cure Parkinson's Trust
Rachel Williams, Parkinson's UK
Megan Evans, WNA Coordinator
Urtha Felda, WNA and MS Society Cymru
Carol Ross, WNA and MDNA
Lesley Williams, Epilepsy Wales
Michelle Herbert, The Brain Tumour Charity
Jean Francis, Ataxia Cymru
Karen Bonham, Whitchurch Hospital
Andrew Wilson-Mouasher, Marie Curie
Natasha Wynne, Marie Curie
Dave Maggs, Headway
Kate Steele, SHINE Cymru
Ann Sivapatham, Epilepsy Action Cymru
Raja Ahmed, Royal College of Psychiatrists
Carol Ross, SWWNA, FibroWales, Restless Legs Wales
Toni Sidwell, The Brain Tumour Charity
Cameron Millar, The Brain Tumour Charity
Jonathon Canty, The Brain Tumour Charity
Sue Wreglesworth, The Brain Tumour Charity
Nathan Sivapatham

Wrexham link - TBC

Apologies Barbara Locke, WNA and Parkinson's UK
Simon Thomas, Assembly Member
WE Parr, MNDA Gwynedd
Ruth Crowder, Wales College of Occupational Therapists
Leigh Campbell, BCUHB

Minutes of the last two meetings and matters arising

Accuracy – spelling of Cath Taffurelli to be corrected.

Minutes of the meetings held on 16th September and 14th November 2014 recorded as true and accurate account.

Co-production

The Chair provided a brief description of co-production as a term that refers to breaking down barriers, recognising the human assets within communities and co-designing and co-delivering services.

Setting the Scene, experience of Neurological Conditions Delivery Plans – David Murray

David Murray introduced himself and mentioned that he is a member of the Welsh Neurological Alliance (WNA) which represents the views of more than 35 third sector neurological organisations in Wales. David gave an overview of the purpose of the Neurological Conditions Delivery Plan and described his role as a WNA patient representative on the plan's Implementation Group as working well.

The WNA has been tasked with leading on the priority of 'raising awareness' of the support provided by various neurological charities and organisations in Wales. The WNA will also be involved in the development of the PROMS and PREMS work.

David indicated that there have been varying experiences of co-production in relation to the development of local delivery plans.

The Chair thanked David for his input and mentioned that Parkinson's Awareness Week is in April and the Flintshire Parkinson's Support Group will be celebrating its 10th anniversary.

Principles and practice of co-production

Ben Dineen of SPICE provided a presentation on the principles of co-production including its origins and examples of co-production in practice and the ethos of 'do with not to'.

The presentation explored a whole system approach to commissioning, design, delivery and evaluation of service provision, with shared power and shared responsibility for all, whereby co-production is an approach to public service delivery within which professionals and citizens work together in equal and reciprocal relationships.

Ben explained that there is currently a timely opportunity to explore co-production in practice due to increased demand for services combined with a reduction in resources.

The time credit currency in use in parts of Wales and elsewhere was described as a way of engaging with and interweaving service user involvement.

Ben provided examples of co-production in action in Wales.

Patient Involvement and Research in Practice

Ana Palazon introduced Professor William Grey of the B.R.A.I.N Unit, Cardiff University and explained that the WNA has worked closely with Professor William Gray who is Professor of Functional Neurosurgery at the Neurosciences & Mental Health Research Institute, Cardiff University School of Medicines as a co-applicant to The Brain Repair And Intracranial Neurotherapeutics (B.R.A.I.N) Unit.

The aim is for the unit to be a Welsh and UK national centre of excellence for delivering novel cell/drug/growth factor therapies to patients with currently untreatable neurological and neurodegenerative diseases. Specifically, Huntington's and Parkinson's diseases, focal Epilepsies and Multiple Sclerosis, thus building a platform for future expansion to other conditions such as Stroke and Dementia as appropriate.

Ana spoke of the importance of patient engagement and involvement at all stages of the research journey.

Professor Gray provided a presentation about the work that will be conducted at the B.R.A.I.N. Unit and its aim to develop new as well as refine existing therapeutics and systems for delivery into the brain to aid brain repair.

Due to a difficult VC connection, it was not possible for colleagues in Wrexham Maelor to see or hear the presentation so it was relayed via mobile telephone by the Professor.

Professor Gray discussed co-production in research, the difficulties presented in co-designing research and how co-production is easier to define and understand in

terms of service provision. The scope for co-design of research is in working together to make research better.

Professor Gray gave the following examples of areas where co-production could be effective:

Making research:

- more relevant via priority setting and grant writing;
- more efficient via input into ethics and protocols;
- more likely to work via recruitment to clinical trials;
- more funding received via public engagement.

Questions and Debate

Urtha Feldman commented that there is a need for LHBs to be more proactive in their approach to the neurological delivery plans and co-production as the engagement of service users and the third sector in the development of some of the plans wasn't as good as it could have been.

Lynne Hughes suggested the CPG could write to the Minister for Health and Social Services to ask about the success of engaging with patients and the third sector in the development of the plans as this is specifically mentioned at the start of the plan. She also asked that the CPG requested that there is a general update on the plans from each Local Health Board. It was suggested that the CPG could make some recommendations to the Minister as to how co-production could become a reality via the delivery plans. (ACTION)

Carol Ross said that the South West Wales Neurological Alliance had a positive experience of the development of the delivery plan for ABMU.

Jean Francis from Ataxia Cymru mentioned the importance of learning from other sectors, such as the work she does with learning disabilities, where people are empowered to be 'in the driving seat.'

Professor Gray made a general point how the most disempowering thing a person has to contend with is the actual illness they are living with and the accompanying treatment processes. The work that he is able to do in rendering people seizure free is empowering in itself.

Carol Ross asked about the role of the GP in co-production. Dr Gray indicated that this should focus around recognition of and referral into research and joining services within the community together that provide care for people.

Ana Palazon suggested that the CPG write to the Royal College of Medicine and the British Medical Association for their view on the role of co-production. (ACTION)

Closing remarks

Mark Isherwood AM summarised the actions from the meeting, thanked all of the speakers and everyone for their attendance and apologised for the problems with the VC and sound issues.

Dates of future meetings:

The dates of the next meetings are 9 June 2015 and 22 September 2015 at 6pm in Committee Room 4, Senedd, Cardiff Bay. There will be a VC link to North Wales.