

Northern Acquired Brain Injury Forum
Minutes of the meeting held on 27.06.2008

In Attendance

Professor Mike Barnes, Paul Saxon, John Donovan, John Welch, Mark White, Catherine Symington, Ben Townsend, Steven McAleese, Vicki Gilman, Jackie Waggott, Fran Mayes, Lindsey Dobson, Lynne Barr, Helen Hastie, Helen Atkin, John Davis, Simon Easton, Katy Collinson, Alister Berry, Kirstie Petley, Amjed Malik, Heather Batey, Kelly Mowbray, Tory Kitwood, Julie Roberts, Simon Richell, Julia Atherton, Viv Watson, Naveem Prabhakaran, Lindsay King, Nick Gutteridge, Janet Grace, Kevin Meares, Alastair White.

Lynne Barr

A copy of Lynne's presentation is available on the NABIF website.

Lynne is based at Middlesbrough PCT but has two roles within the region:

1. Implementation of the NSF for long term neuro-conditions in the South of Tees Region;
2. Co-ordinating the review of services across the region, with a view to implementation of the NSF.

Lynne has created the North East Neurosciences Network, a commissioning network with commissioner representation from each of the PCT's in the region: North of the Tyne, South of the Tyne, Durham and Darlington, Teesside and Cumbria.

Lynne has a clinical background (OT), in rehabilitation, health and social care. She has experience managing clinical services; Physical Disability Services; Partnerships Manager, leading integration across health and social care; and has worked for many years with the Care Services Improvement Partnership (CSIP).

The remit for the Network is service reform and improvement across the region, measuring the service against the 11 Quality Requirements set out in the NSF.

The remit includes:

- Future commissioning and redesign function;
- A long term conditions strategy;
- Making services relevant to the users of those services and providing them with choice and the ability to choose.

Lynne was keen to emphasise the size of the project being undertaken and its complexity. It is a long term project, but so far Lynne is only about 6 months in post.

The present emphasis is on creating the commissioning network, establishing the links with experts and service providers in the region, engaging with service users at a local level (for example through the Neurological Alliance and the Carers Forum) and creating stakeholder groups for each PCT.

The key issues will be:

1. Collecting data sets: from primary, secondary health services and social care.
2. How to approach treatment pathways across the range of conditions covered by the NSF.
3. Gathering and disseminating information (the Knowledge Centre at Walkergate Park being a good example of how this can be done).
4. Workforce planning: identifying and capturing the skills needed and using them to improve standards and competencies across the region.
5. Carrying out baseline audits across the region.
6. Effective commissioning, with emphasis on joint commissioning.
7. Leadership, to make the North East Neurosciences Network credible.

There are some positive results for the network so far. All the PCT's have shown a willingness to engage. Funding has been obtained for the Neurological Alliance in Teesside and North Yorkshire to assist in information gathering, provision and networking with other organisations.

Funding (£50,000) has been obtained for carrying out clinical reviews, audits and network developments. Working groups have been set up and are active, and will present their findings in September.

A baseline audit has been carried out by Middlesbrough PCT (for Middlesbrough and Redcar). The audit was carried out using the conditions set out on the Long Term Conditions website, auditing against the requirements of the NSF. To cope with the size of the task the audit was carried out by gathering together a stakeholder group, including representatives from the Local Authorities (Housing, Social Care, Legal Support, Telecommunications and Equipment), Patient Groups, GPs, Carers Groups, Commissioners of Services, Community Matrons, Specialist Providers (including providers of rehabilitation), Specialist Nurses, Consultants and providers of palliative care.

The representatives were asked to assess existing services against the requirements of the NSF, using an electronic voting method to assess whether each service was provided, partially provided, planned or not provided.

The plan is to role out this exercise to other areas in the region. However, first it is necessary to set up stakeholder groups for each region.

NABIF could play a helpful role, having already established a network amongst service providers in the region, from the statutory, independent and voluntary sectors. It could therefore play a role in helping the Network to identify where expertise lies within the region.

Lynne agreed to provide NABIF with information and updates from the Network so that we can engage where appropriate.

Business Meeting

1. Apologies for absence

John Llewelyn, Boda Gallon, Andrew McDonald, Barbara Chandler, Julie Young, Des O'Meara, D Moore, Janice Thomson, Janis Smith, Annie Baxter, John Walker.

2. Minutes of the last meeting

Agreed.

Matters arising: Mike Barnes, Des O'Meara and Steven McAleese attended the UKABIF meeting on 20th May 2008. The purpose of the meeting was to bring together the regional ABIF's to strengthen the network.

The ABIFs remain keen to be loosely affiliated, with each other and with UKABIF, but with no formal links. There are a number of regional ABIFs trying to get off the ground, and it is hoped to put together a tool kit to assist.

UKABIF will also consider providing a data resource through its website. They are keen to help with media relations and organisation of local conferences.

The plan is to have such meetings once every 6 months.

3. Service mapping project update

Simon Easton provided an update.

The information gathering has been completed. There have been discussions with the website designer (who created the NABIF website) and we are awaiting an estimate for the costs of creating a suitable data base.

4. October conference

Arrangements for the conference are well advanced. Details have been circulated of the venue and programme. They are also available on the NABIF website.

All members of NABIF are encouraged to support the conference. It is hoped the conference will raise funds needed to support the service mapping project, but it is also an opportunity for NABIF to establish a presence and to expand the network.

5. Neurological Alliance and Headway update

Alistair White, North East Regional Co-ordinator for Headway, provided an update.

The **Neurological Alliance** is a wide range of neurological charities and stakeholders, which have come together to make life better for people with a neurological condition. There is a well established group based at Teesside, covering the Tees Valley, Durham and North Yorkshire Areas. It was launched in November 2006 with the aims of:

- Raising awareness of neurological conditions and their impacts;
- Informing and influencing policymakers of the needs of people with neurological conditions;
- Securing high standards of service;
- Promoting research and the dissemination of information.

The network has recently secured £72,000 over three years from local PCT's to employ a Regional Co-ordinator for Neurological Services. The group has also had involvement in strategic meetings with the Strategic Health Authority, PCT's and Oversight and Scrutiny Health Committees of Local Authorities.

Organisations involved include Headway, MS Society, MND Association, ADDER, Brain Tumour Support, National Society for Epilepsy, The Stroke Association, Regional Hospices, The Shaw Trust.

A conference "*People who need people*" has been organised at Wynyard Hall on 7th November 2008.

The North Cumbria, Northumberland and Tyne and Wear Neurological Alliance is to be officially launched on 6th October 2008. Organisations involved so far are Headway, MS Society, Epilepsy Action, National Autistic Society, MDN Association and ADDER.

Further information is available from Alistair White by e-mail to ne.regional.co-ordinator.headway.org.uk or from the Neurological Alliance website: www.neurologicalalliancenortheast.org.uk.

Headway aims to promote understanding of all aspects of brain injury and provide information, support and services to people with brain injury, their families and carers.

There are now four branches in the North East: Teesside, Tynedale (based at Hexham), Gateshead, and North Northumberland (based at Berwick).

Plans are already in place to launch a branch in Durham and Chester le Street, with a public meeting due to take place on 23rd September 2008. Again, further information is available from Alastair White at ne.regional.co-ordinator.headway.org.uk

A steering group is being put in place to establish a Newcastle and North Tyneside Branch.

6. Introductions

John Donovan, Hunters Moor: John introduced Hunters Moor, established this year by himself and Mike Barnes to provide home based rehabilitation to people who have suffered a brain injury. They are currently based in the North East, but plan to have a base in the North West of England by the end of the year. In addition to rehabilitation, services include treating with botulinum and a consultancy service.

Katy Collinson: Katy is a Clinical Neuropsychologist providing services at Walkergate Park and also at Sunderland. There has been a gap in services at Sunderland for 2 years, with most patients being referred to Dr John Welch at Newcastle General Hospital. The neurologists at Sunderland have had little in the way of a neuropsychology service and also very little sign-posting of services. At the moment Katy is working through a backlog of referrals (assisted by Tom Kelly), concentrating on carrying out assessments, but without the capacity at the moment to provide therapy. She is also only able to accept referrals from neurologists in Sunderland. This service is currently under review and Katy hopes to be in a position to provide the full range of services required.

Kevin Meares: Kevin has recently created, with Dr Sally Standart, the North East Traumatic Stress Clinic. The Unit provides specialist treatment for PTSD, and both Kevin and Sally have considerable expertise in the use of EMDR and CBT. This service was started 1st April 2008 and aims to provide treatment, training and supervision of others, and research into PTSD. They also have medico-legal expertise.

For further information please contact Kevin Meares at kevin.meares@ntw.nhs.uk.

7. Any other business

None.

8. Next meeting

The next meeting will take place on Friday 3rd October 2008 at St James Parish Church Centre, St James Road, Carlisle, CA2 5PD.