

HEALTH SCRUTINY PANEL

24 AUGUST 2011

**NEUROLOGICAL CONDITIONS:
INITIAL EVIDENCE FROM NORTH EAST NEUROSCIENCES
NETWORK**

PURPOSE OF THE REPORT

1. To provide an introduction to the Panel's next area of study, which is Neurological Conditions.
2. To introduce representatives from the North East Neurosciences Network, in attendance to provide an initial briefing for the Panel.
3. To suggest, for the Panel's consideration, DRAFT Terms of Reference to direct the investigation.

RECOMMENDATIONS

4. That the Panel notes the introduction to Neurological Conditions.
5. That the Panel notes the evidence supplied by the North East Neurosciences Network and makes any enquiries felt pertinent.
6. That the Panel considers the DRAFT terms of reference, outlined later in this report, purpose and following any amendments, accepts them.

Introduction to Neurological Conditions

7. Neurological Conditions are very common in the UK. They affect a wide range of people, to differing levels of severity, yet the average person does not know a great deal about them, or what the term 'neurological conditions' covers.
8. According to figures published by the *Neurological Alliance*, there are around 10 million people in the UK living with a neurological condition, which has a

significant impact on their lives¹. The Neurological Alliance predicts that the number of people with neurological conditions will grow sharply in the next two decades due to improved survival rates, improved general health care, infection control, increased longevity and improved diagnostic techniques.

9. The following text, taken from the Neurological Alliance website, outlines some useful introductory information about Neurological Conditions:

9.1 *Neurological conditions result from damage to the brain, spinal column or nerves, caused by illness or injury. Many of the precise causes of neurological conditions are not yet known. Neurological conditions affect young and old, rich and poor, men and women and people from all cultures and ethnicities.*

9.2 *Some neurological conditions are life-long and people can experience onset at any time in their lives. Others, such as cerebral palsy, are present from birth. Some conditions, such as Duchenne muscular dystrophy, commonly appear in early childhood, some, such as Alzheimer's disease and Parkinson's disease affect mainly older people.*

9.3 *There are also conditions which have a sudden onset due to injury or illness, such as a head injury or stroke, or cancers of the brain and spine. Some neurodegenerative conditions, such as multiple sclerosis and motor neurone disease, affect people mainly in adulthood and will cause deterioration over time, affecting a person's quality of life and their ability to live independently.*

9.4 *Some neurological conditions are life threatening, most of them severely affect people's quality of life and many cause life-long disability. Caring for someone with a debilitating illness often means that carers have to give up their own employment, in addition to the person with the condition being unable to continue to be economically active. This will have a devastating impact on the family's economic situation.*

9.5 *Neurological conditions are very poorly understood by the general public. Levels of awareness are low even about relatively common conditions, such as epilepsy. There are also a large number of rare conditions, such as Guillain-Barré syndrome and ataxia-telangiectasia, which are largely unheard of by most health and social care professionals².*

INTRODUCE REPRESENTATIVES FROM NORTH EAST NEUROSCIENCES NETWORK

10. Today's evidence from the North East Neurosciences Network (NENN) is intended to provide a useful introduction for the Panel on the issues faced by Neurological patients, their families and the services they rely upon. The NENN will be represented by its Chair, with supporting colleagues.

¹ Please see *Neuro Numbers*, Published by the Neurological Alliance, ISBN 1901893324

² <http://www.neural.org.uk/living-with-a-neurological-condition/what-is-a-neurological-condition>

11. The following text is from the NENN's website³ and provides the Panel with useful background information on the NENN.
- 11.1 *The North East Neurosciences Network (NENN) was established in 2008 to promote the delivery of the National Service Framework for Long Term Neurological Conditions through a collaborative approach to commissioning across the region. This includes cross sector and cross agency working, involving user and carer groups and the third and independent sectors.*
- 11.2 *NENN is a multi-stakeholder model supported by reference groups, task orientated work groups and workstreams.*
- 11.3 *NENN reports to the regional Directors of Commissioning Group and the regional Directors of Adult Social Services (ADASS) through the Regional Disability Group.*
- 11.4 *The intentions of the Network are to ensure delivery of timely, appropriately informed, skilled services closer to peoples homes, in the community. Standards of access and services will be as consistent as possible across the region, with increased choices of options to remain living independently in the community.*

NENN promotes:

- *A partnership approach, based on respect, between statutory and voluntary organisations and people and their carers in receipt of services.*
- *An integrated approach to care (both vertically and horizontally) to provide seamless services.*
- *The Social Model of Disability in all services*
- *Patient, public involvement and engagement*
- *Equity, equality and diversity in care provision*
- *Efficiency and the best use of time and resource*
- *Quality information, advice and access to evidence/effective interventions and outcomes.*

12. It is anticipated that the NENN will be able to provide detailed information about neurological services, from a number of perspectives, given its multi-agency membership model. On behalf of the Panel, the NENN has been given a fairly 'blank canvas' to speak about the most pertinent neurological issues, as it sees them. In addition, the Network has also been asked to address the following specific themes.

- 12.1 Could the NENN outline a brief history of Neurological Services in the North East, in recent years?

³ <http://www.nenp.org.uk/nenn/about-us.aspx>

- 12.2 For the past five or six years, the planning & development of Neurological Services has been guided by the National Service Framework for Long Term Neurological Conditions. What impact, if any, have recent Health Policy Developments had on the provision of, and future for, Neurological Conditions?
- 12.3 What is the Network's view of how Neurological Services currently perform in Middlesbrough & the wider North East? What information sources does it base this view on?
- 12.4 Are there any areas of Neurological service that are particularly well developed? Are there any areas of service that require development?
- 12.5 What, in the view of the Network, are the future prospects for Neurological Services in Middlesbrough?
13. The NENN has submitted a paper for the Panel's consideration, which outlines its views on Neurological Services, as well as addressing the themes outlined above (Appendix 1). It is anticipated that the NENN representatives will initially speak to the paper, highlighting the salient aspects of the paper, ahead of addressing questions from the Panel. It is anticipated that the discussion with the NENN will identify further avenues of enquiry that the Panel will want to pursue in subsequent meetings.
14. Following consideration of the attached paper and the accompanying debate, the Panel is asked to consider its next step in the consideration of Neurological Services. It could be that the Panel would like to pursue particular sources of evidence such as patient/carer groups, health and social care commissioners, provider organisations and expert associations concerned with neurological conditions.
15. In addition, with the benefit of holding the discussion today, the Panel is asked to consider, amend where appropriate and approve the following terms of reference, drafted to guide the investigation into Neurological Conditions.

DRAFT Terms of Reference

- 15.1 To gain a detailed understanding of what is meant by, and classified as, *neurological conditions*
- 15.2 To establish the extent to which neurological conditions affect the population of Middlesbrough
- 15.3 To establish what services are available for neurological conditions in Middlesbrough, including the level of diagnostic and assessment support.

- 15.4 To gather the views of interested parties on the current performance of neurological conditions in Middlesbrough and to ascertain how those services need to develop to meet future challenges.
- 15.5 To draw conclusions and make recommendations as the Panel views as appropriate, on the basis of the evidence received.

BACKGROUND PAPERS

16. Appendix 1 – Briefing Paper prepared and submitted by the North East Neurosciences Network
17. *Neuro Numbers – a brief review of the numbers of people in the UK with a neurological condition.* © Neurological Alliance April 2003. ISBN 1901893324.

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