



## **National Leadership Group: Improving the lives of people with neurological conditions**

### **Terms of reference**

#### **Purpose**

The purpose of the Group is to bring together key opinion leaders in the field to drive forward the development of neurological services and improve the lives for people living with a neurological condition.

#### **Background**

The Neurological Alliance is the only collective voice for more than 70 national and regional brain and spine organisations working together to make life better for 8 million children, young people and adults in England with a neurological condition.

Our vision: A better quality of life for each individual diagnosed with a neurological condition

Our mission: To raise awareness and understanding of neurological conditions to ensure that every person diagnosed with a neurological condition has access to high quality, joined up services and information from their first symptoms and throughout their life

The Neurological Alliance National Leadership Group: Improving the lives of people with neurological conditions grew out of the stakeholder group which was created to assist in the implementation of the National Service Framework for Long Term (Neurological) Conditions. The NSF was published in 2005 and set up a 10 year timescale for the implementation of 11 quality requirements (QR).

In the light of changes in the policy landscape in health and social care in 2010, in particular the focus on patient outcomes, there was a requirement to reframe the terms of reference of the National Leadership Group and subsequently, with the change in architecture of the NHS following the introduction of the Health and Social Care Bill an opportunity to involve new and different stakeholder groups.

The National Leadership Group enables patient organisations and professionals, to shape the strategic direction and to monitor progress of current health and social policy, and provide a forum to contribute to the on-going debate as to how this should be planned.

**Role**

- To bring together the leaders in the neurology community to champion and promote services that meet the needs of people with neurological conditions.
- To raise the profile of neurological conditions.
- To act as a resource of specialist knowledge and opinion on behalf of people with neurological conditions for Department of Health, commissioners and providers.
- To oversee and review progress of policy that impacts on people living with neurological conditions.
- To develop tools and resources to support the commissioning of services for neurological conditions.
- To develop quality standards, promote good practice and ensure that this is implemented across the NHS and social care.
- To promote the involvement of service users and carers to shape the development of neurological services.

**Membership**

- The Group will be co-chaired by the Department of Health Clinical Neurosciences Advisor, Dr Chris Clough and the Chair of Trustees of the Neurological Alliance, Steve Ford
- The Group brings together neurological charities that represent the needs of their patient groups with the Department of Health, commissioners and providers of health and social services along with the main professions involved in delivering the care to patients with neurological conditions.
- Membership will be reviewed annually to reflect changing priorities.
- Task and finish group members may be drawn from outside the Group at the discretion of the Chairs.

**Meetings**

- Meetings will initially take place four times a year in London
- The group will stay in regular contact between meetings and facilitate the sharing of information with a wider group
- Quorum for meetings of the Group will be 50% of the membership including the Chairs
- The Group will aim for consensus. Should a vote be required, this will be via a show of hands and it will be noted in the minutes. If required, the Chair will have the casting vote.
- Members must declare any conflicts of interest at the beginning of the meeting. The Chairs will be decide if this will preclude the member from all or parts of the meeting
- Members can nominate a named deputy to attend meetings of the Group on their behalf.

**Secretariat**

- This will be provided by the Neurological Alliance.
- Minutes of each meeting will be shared with members to allow comment on factual accuracy and approved by the Chairs to allow them to be published in a timely manner

