



Engagement exercise on the Long Term Conditions Outcomes Strategy

Neurological Alliance response

1. About the Neurological Alliance

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 is for a better quality of life for each individual diagnosed with a neurological condition. Our mission is 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, throughout their life.

2. Overview

The Neurological Alliance welcomes the development of the Long Term Conditions Outcomes Strategy (LTCOS) and fully supports its ambition to enhance outcomes for all people with long term conditions throughout their lives. A large proportion of neurological conditions are long term and given that many of the outcomes desired by people with neurological conditions are common to all long term conditions, we appreciate the potential value of this strategy.

In order for the LTCOS to achieve its potential and improve outcomes for those with long term neurological conditions, it must address key issues currently not emphasised in its scope such as complexity, specialist needs and rehabilitation.

Additionally, the LTCOS must be regarded as part of a broader approach to achieve vital improvements in neurological outcomes. The LTCOS alone cannot resolve the years of neglect; only in conjunction with a robust LTCOS implementation plan, Strategic Clinical Network for neurology, the early development of both neurological Quality Standards and NHS Commissioning Board (NHS CB) guidance and the proportionate inclusion of neurology specific indicators in the Commissioning Outcomes Framework will improvement occur. It is unrealistic to expect for appropriate services for people with neurological conditions to be commissioned through the LTCOS without additional levers and incentives.

Whilst the generic LTCOS has been cited during the Neurological Alliance's recent 'Better deal for neurology' campaign as the strategy under which neurology will sit in the future, not all neurological conditions are long term. In order to meet the needs of the 8 million people with a neurological condition in England equitably under the new health and social care arrangements the Department of Health and NHS CB need to take the full spectrum of neurological conditions into consideration in current and future policy development.

We believe that, if underpinned by a robust implementation strategy including accountability mechanisms, the LTCOS has the potential to help drive improved outcomes.

3. The nature of neurological conditions and the scope of the LTCOS

Conditions on the neurological spectrum are diverse: some are stable, others are characterised by sudden onset, many are intermittent and unpredictable and a large proportion are progressive. The vast majority are rare and all are complex.

Despite the fact that not all neurological conditions are long term, neurology has been placed wholesale within the scope of the LTCOS from the outset of its development. It remains unclear how the LTCOS will deliver for conditions that are rapidly progressive where life expectancy is very short, such as motor neurone disease, or for those not always long term, such as acquired brain injury.

With Ministers and the Department of Health continuing to signpost the LTCOS in respect of all neurological conditions, we have real concerns that the conditions that fall outside of the strategy's scope will be overlooked as commissioners will not have appropriate support and direction on how to deliver the best outcomes for these individuals.

4. The profile of neurology under the long term conditions umbrella

Neurological conditions are largely poorly understood by health and social care professionals alike. This has resulted in the historic neglect of neurology which successive administrations have mirrored in terms of their policy priorities, placing neurology in the 'too difficult' category.

Professionals' lack of awareness and in-depth knowledge around neurological conditions impacts significantly on the quality of life of people with neurological conditions, from diagnosis onwards. This causes stress and anxiety and delays access to treatment and management which may accelerate progression of the condition and increase the consequent burden across multiple systems.

In order to address the improvements required as outlined in the recent key reports by the Association of British Neurologists and the Royal College of Physicians¹ and the National Audit Office (NAO)², professionals need to be encouraged to engage with, and prioritise neurological conditions. A solution to this would be to granting neurology some individual prominence within the strategies, frameworks and levers of the new health and social care system. If neurology sits in the LTCOS under the umbrella of long term conditions, it is inevitable that clinical commissioning groups will prioritise more common conditions in their commissioning decisions.

Neurology is exclusively categorised under long term conditions in both the NHS Outcomes Framework and Commissioning Outcomes Framework, and without a commitment that the confirmed neurology specific NICE Quality Standards will be prioritised, the new system is not rigged to deliver improvements in neurological outcomes at the pace and scale necessary before the National Audit Office review neurological services in 2014.

5. What the LTCOS needs to include from a neurological perspective

In order to ensure that, when implemented, the LTCOS can play a proactive role in improving outcomes for people with long term neurological conditions and others, the strategy must incorporate the following themes:

¹ *Local adult neurology services for the next decade* - Royal College of Physicians and Association of British Neurologists, June 2011

² *Services for people with neurological conditions* - National Audit Office, December 2011

5.1 The need for early and accurate diagnosis by and access to a specialist

Achieving early and accurate diagnosis is essential for all people with neurological conditions, without which they cannot access appropriate and timely care, support and, where available treatment. Delay in diagnosing encephalitis, for example, could result in debilitating acquired brain injury or death.

5.2 Timely access to rehabilitation

Whilst rehabilitation is not applicable to all long term conditions, the ability to access rehabilitative services is crucial for people with neurological conditions such as Guillain-Barre syndrome, stroke and multiple sclerosis. Rehabilitation can help prevent further complications, retain independence and allow the individual to return to normal life as quickly as possible; this enhances quality of life, reduces the financial burden on health, social care and welfare budgets and reduces the risk of readmission.

5.3 The importance of multidisciplinary team working

Individuals with a neurological condition can access up to 30 different services within their lifetime. It is therefore essential that the individual's care, from diagnosis through to end of life care, is coordinate by a multidisciplinary team, which works across health and social care and where appropriate includes an individual care plan. For neurology, multidisciplinary team may comprise professionals including but not limited to neurologists, specialist nurses, clinical psychologists, specialist physiotherapist, specialist occupational therapist, social workers, mental health support and speech and language therapist and dentists.

5.4 Process for and prevention of emergency/unplanned hospital admissions

Where an individual with a neurological condition attends Accident and Emergency on an unplanned or emergency basis, they need access to neurological expertise and to, where relevant, to be referred to the relevant services urgently, as is the case for epilepsy for example.

In respect of preventing unplanned hospital admissions, shared protocols and pathways of care between primary and secondary care are essential. Care plans and self management can also prevent unnecessary hospital admissions for those with complex care requirements. This must be a priority within the context of the LTCOS.

5.5 Ongoing care and monitoring

The majority of people with neurological conditions are placed back under the care of a GP following diagnosis and the receipt of an initial management plan. As GPs will not necessarily know how to manage a large proportion of neurological conditions, M.E. providing a common example, many people are left with no ongoing care, management or monitoring of their condition, until they deteriorate significantly. The LTCOS presents a real opportunity to highlight the importance of ongoing care and management including end of life care.

6. Implementation of the LTCOS

Since 2005, neurological services and outcomes have been driven by the National Service Framework for Long Term Conditions (NSFLTC). By design, the NSFLTC did not have the traditional levers to support implementation, including national monitoring, targets and ring-fenced funding for specific initiatives. As documented by

the recent NAO and Public Accounts Committee reports on services for people with neurological conditions³, the impact of the NSFLTC on service provision and improving outcomes was limited, characterised by significant variation across the country.

The NSFLTC represents a vital learning opportunity for the Department of Health and NHS CB and this learning can be applied directly to the LTCOS. We are extremely concerned, however, that implementation of the strategy will be a matter for local determination and will not benefit from the experience of the NSFLTC. We urge the NHS CB to develop a robust and adequately resourced implementation strategy, including accountability mechanisms, incentives and national monitoring criteria and call for this requirement to be included in the forthcoming NHS Mandate.

In the development of both the LTCOS and its implementation strategy, we urge the Department and NHS CB to consider how the LTCOS will work with other related strategies, including the forthcoming UK Plan for Rare Diseases and the 'Fulfilling Potential' disability strategy, to ensure these strategies are complementary and describe a coherent vision for individuals to whom multiple strategies are relevant.

Sally Percy
Policy and Public Affairs Officer, Neurological Alliance

15 June 2012

³ *Services for people with neurological conditions* - National Audit Office, December 2011; *Services for people with neurological conditions* - Public Accounts Committee, March 2012