

Consultation on the Commissioning Outcomes Framework indicators

Neurological Alliance response

1. Overview

We welcome this consultation on the Commissioning Outcomes Framework (COF) indicators.

Given the central importance of the COF in holding clinical commissioning groups (CCGs) to account under the structural arrangements proposed in the Health and Social Care Bill, the Neurological Alliance is extremely disappointed by the prohibitively short period for which this consultation has run.

The timescale imposed is of particular concern in light of the complexity of the consultation, which requires consultees to cross reference multiple related policy documents, such as the NHS Outcomes Framework, in order to respond comprehensively.

Indeed for many of our members, the considerable time commitment required has rendered engagement with this crucial consultation a practical impossibility.

We strongly believe that a consultation period of 12 weeks would have been appropriate in this instance and urge NICE to provide ongoing and meaningful opportunities for stakeholder engagement in the COF indicator development process.

2. The scope of the COF

The Neurological Alliance does not regard the COF as sufficiently broad in focus given that of the 324 named neurological disorders¹, with the exception of stroke, dementia and epilepsy, neurology is omitted from its scope.

The rationale for this omission is unclear. There are 8 million² people living with a neurological condition in England, with approximately 1 in 10 general practitioner consultations³ relating to a neurological condition. At an annual cost to the NHS of £4.3 billion⁴, there can be no question that neurology should be a priority area for the health service. However, whilst the COF indicators broadly afford priority to those conditions where NHS expenditure is greatest, this correlation does not apply to neurology. This stark underrepresentation is cause for serious concern.

The need for the proportionate inclusion of neurology specific indicators in the COF is underlined by the National Audit Office's (NAO) recent report on services for people with neurological conditions⁵. The report finds that, despite a 38 per cent real terms increase in investment in neurological services between 2006-07 and 2009-10⁶, care for people with neurological conditions remains fragmented, poorly coordinated, and

¹ *National Service Framework for Long Term Neurological Conditions* - Department of Health, 2005

² *NeuroNumbers* - Neurological Alliance, 2003

³ *Local adult neurology services for the next decade* - Royal College of Physicians and Association of British Neurologists, June 2011

⁴ [Programme budgeting data 2010-11](#), Department of Health

⁵ *Services for people with neurological conditions* - National Audit Office, December 2011

⁶ *ibid*

variable in terms of both quality and access. Consequently, the challenge that health and social care services face in relation to neurology requires urgent prioritisation.

The NAO concludes that without national monitoring and outcome targets and indicators, the Department of Health has been unable to track progress on neurology service improvement or to hold local commissioners to account. These conclusions represent an important learning opportunity for the NHS and so, whilst the Department of Health is very clear on the central importance of accountability mechanisms under the proposed NHS structure, it is deeply worrying that the COF does not give neurology the prominence necessary to incentivise CCGs to deliver vital improvements in care and support for people with neurological conditions.

3. Incentivising CCGs to deliver appropriate neurology services

There can be no doubt that CCGs will require incentives to ensure that neurology is given appropriate priority, particularly in the context of the historic neglect to which neurology has been subject. This is most recently apparent in the failed implementation of the National Service Framework for Long Term Neurological Conditions (NSFLTNC), the mid point review of which was cancelled by the Department of Health in 2010. However, a charity consortium conducted an independent review which found that not one PCT had fully met a single NSFLTNC quality requirement and only 13% of PCTs had met evidence based markers⁷.

That no GP consortia pathfinder has registered neurology as a special interest strongly indicates that neurology will continue to be neglected in the future unless its prioritisation is compelled by the explicit inclusion of neurology in accountability frameworks and incentive schemes.

Given that some CCGs will cover a relatively small population area and are under no duty to collaborate with other CCGs in commissioning services for people with less common conditions, there is a real risk at CCG level that individual neurological conditions will be overlooked. The COF should play a vital role in ensuring that CCGs are proactive in tackling the neurology challenge, but in the absence of neurology specific indicators this challenge will go unmet to the detriment of service users, the NHS and tax payers.

4. Neurology and the long term conditions umbrella

Whilst we welcome the inclusion in the COF of indicators with a focus on people with long term conditions, we do not feel that these alone will be adequate in guaranteeing the provision of appropriate care and support for people with neurological conditions.

Neurological conditions are complex disorders of the brain and or nervous system; some are neuro genetic, some brought on through disease, some are sudden onset. The complex and uncommon neurological conditions require skilled multi professional services, rehabilitation and in many cases progressive disease or major brain injury require skilled ongoing care services. If neurology sits in the COF only under the umbrella of long term conditions, it is both inappropriate given that not all neurological conditions are long term and inevitable that CCGs will prioritise more common conditions in their commissioning decisions.

⁷ Half way there - are we half way through: A mid-term review of the, National Service Framework for Long Term Neurological Conditions - Neurological Commissioning Support, 2010

5. Integrated care

We also note the focus of the COF on clinical outcomes and question the absence of outcomes related to the delivery of integrated care between primary, secondary and social care services. Access to integrated health and social care services is paramount to enabling individuals with neurological conditions to achieve the highest quality of life possible. However, for the vast majority of people affected by neurological condition, joined up, high quality care remains an aspiration.

Unless it is intended that there will be another tool by which the NHS Commissioning Board can monitor CCGs against their duty to promote integrated health and social care services, the Alliance regards this as a major oversight. If the scope of the COF is not broaden, it will be not be able to deliver the outcomes of greater integration envisaged by the Health and Social Care Bill.

6. Quality standards

With the development of a number of neurology Quality Standards currently awaiting confirmation, we strongly support the inclusion of both condition specific and pan-neurological indicators in the COF to reflect the priorities that CCGs will be taking forward in the coming years.

7. Developing neurological COF indicators

With regards to the development of neurological indicators to sit in the COF, the Neurological Alliance highly recommends the adaptation of the NSFLTNC quality requirements as outcome indicators; the NSFLTNC remains a rich resource and we would welcome the opportunity with to work with NICE to assist in the development of neurology indicators.

8. Summary

In summary, the NAO will be conducting a follow up review to its report on neurology services by 2015. Without neurology being explicitly embedded in the COF, and in the absence of a national neurology lead, neurology Strategic Clinical Networks and a neurology outcomes strategy, the Neurological Alliance is deeply concerned that no provisions will be made to drive the improvements in neurological services for which the Department of Health will be held accountable.