Written evidence submission from the Neurological Alliance to the Health Select Committee inquiry on the National Institute for Health and Clinical Excellence (NICE)
29 October 2012

1. About the Neurological Alliance

1.1 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.

1.2 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. Summary

2.1 We welcome the opportunity to submit evidence to the Health Select Committee's inquiry on NICE. Our submission focuses on the role of NICE quality standards.

2.2 Recent reports by the National Audit Office[1] (NAO) and Public Accounts Committee[2] (PAC) have vividly described the parlous state of neurological services in England. Both reports conclude that care for people with neurological conditions is currently characterised by fragmentation, a lack of coordination and regional variation resulting in poor outcomes for service users and poor value for money for the NHS. The need for improvement in this complex and historically neglected area is urgent but following the Government's rejection[3] of many of the PAC's recommendations on how the outcomes and cost effectiveness of neurological care could be enhanced, there are concerning signs that neurology is once again being sidelined under the reformed NHS.

2.3 Together with the strategic clinical network (SCN) for mental health, dementia and neurological conditions, the 15 confirmed neurology-specific NICE quality standards are currently the central drivers for improvements in neurological care under the new NHS arrangements. We do not regard the SCN and quality standards as capable alone of achieving improvements of the scale and at the pace necessary; they must be part of a broader strategy if the NHS Commissioning Board (NHS CB) and Department of Health are to successfully address the legacy of failure ahead of the neurological services progress review, which the PAC has indicated it intends to direct the NAO to conduct in 2014. Nonetheless we do believe that, once developed, quality standards could play a vital role in providing commissioners with much needed support in giving due priority to neurological conditions in their commissioning decisions and in delivering high quality, cost effective neurological care.

2.4 However, we have a number of concerns relating to quality standards, specifically the:

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[1] *Service for people with neurological conditions* - National Audit Office, December 2011
[2] *Services for people with neurological conditions* - House of Commons Committee of Public Accounts, Seventy-second report of Session 2010-12, 27 February 2012
[3] Treasury minutes: Government responses on the Sixty Eighth, the Seventieth, the Seventy Second and Seventy Fourth reports from the Committee of Public Accounts: Session 2010-12 - pp. 14 - 20

- slow pace at which quality standards are being developed and undetermined process by which quality standards will be prioritised for development;
- fast tracking of quality standards for a condition or condition area that has an existing NICE guideline, which will have the effect of prolonging neglect in areas without NICE accredited guidance;

- extension by four years of the deadline for all 180 quality standards to be developed from 2015 to 2019;

- status of quality standards as one of only two means by which a condition or condition area can be included in the key commissioning accountability framework, the Commissioning Outcomes Framework (COF), which will have a substantial influence over commissioning priorities and from which neurology is currently largely omitted;

- unreasonable weight of expectation placed upon neurological quality standards, in the absence of any other quality, accountability and improvement mechanisms under the reformed NHS, to deliver urgent, large scale improvements to neurological services.

2.5 It is clear that clinical commissioning groups (CCGs) are not being equipped to tackle the huge challenge that neurology represents and that in the absence of additional quality accountability, incentive mechanisms or national neurology strategy, neurological quality standards will perform an absolutely critical role both prompting CCGs to commission, and be supported in the delivery of, appropriate services for people with neurological conditions.

2.6 As such, we will be calling on NICE to prioritise the unscheduled neurological quality standards for development in 2013.

3. The role of NICE quality standards in the new NHS system architecture

NICE quality standards and neurological conditions

3.1 Of the 180 quality standards that NICE is due to develop by 2019, a deadline recently extended from 2015, a total of 15 relate specifically to neurology[4] with 11 focussing on individual conditions. In addition, a quality standard for rarer neurological problems has also been confirmed; this is an extremely important development for the substantial number of neurological conditions for which there has never been NICE generated guidance. We strongly support the announcement of all 15 neurological quality standards and are ready to work with NICE where appropriate to assist in their development and promotion.

The pace of quality standard development

3.2 However, the positive role that quality standards could play within the new commissioning model is being fundamentally undermined by both the speed at which they are being developed and the continued lack of clarity on the development timetable.

[4] Autism (adults); autism (children and young people); epilepsy (adults); epilepsy (children); head injury; headaches/migraine (young people and adults); multiple sclerosis; Parkinson's disease; faecal incontinence; delirium; management of transient loss of consciousness in adults; motor neurone disease; neurological problems (relatively uncommon neurological problems e.g. muscular dystrophy); dementia; stroke

3.3 To date, just two neurological quality standards have been published[5], with only a further two in development[6]; none of the remaining neurological quality standards have been scheduled in the development programme. In addition to impacting detrimentally on the ability of CCGs to commission high quality, cost effective services for these conditions, the lack of published neurological quality standards effectively debars neurology from inclusion in the COF, the key commissioning accountability framework (see paragraphs 3.9-10).

3.4 NICE and the Department of Health have yet to establish the basis on which undeveloped quality standards will be prioritised and, from this, publish a development timetable. The only criterion for prioritisation identified to date is that those conditions or areas with a confirmed quality standard that have an existing NICE guideline will be fast tracked for development.

3.5 As NICE guidelines will continue to act as a source of guidance to commissioners under the new system, we do not consider this criterion is an appropriate basis for quality standard prioritisation; its unintended consequence will be that those conditions for which there is no guideline at present will continue to be unaddressed in the early period of CCG operation, leaving commissioners unsupported often in the most complex and challenging areas. Indeed, as the vast majority of neurological conditions have no NICE guideline, so the creation of all the confirmed neurological quality standards, including the overarching standard for rarer neurological problems, needs to represent an urgent priority for NICE.

3.6 We note with great concern that an additional four years has been added to the original timetable for quality standard development, with the full suite now not due to be completed until 2019. This presents a considerable problem for commissioners, who will not be able to use the full suite of quality standards to support their commissioning decisions and the delivery of comprehensive, value for money care and support as intended for six years from the date CCGs become operational.

3.7 In consideration of the acute need for support that commissioners will have in respect of driving neurological improvements and the dearth of neurology specific accountability and incentive mechanisms in the new system (see paragraphs 3.11-22), we will be calling on NICE to commit to develop in 2013 all neurological quality standards on which work has not yet commenced.

3.8 The imperative to deliver service improvements and enhance outcomes for neurological conditions is particularly urgent in light of the progress review on neurological services that the PAC has expressed an intention to instruct the NAO to undertake in 2014. If neurological quality standards are to play a substantive role in delivering improvements of the scale and at the pace necessary, they will need to be developed as soon as possible; waiting until 2014/15, let alone until 2015 onwards, will be too late.

Quality standards and the Commissioning Outcomes Framework

3.9 The importance of publishing the quality standard development timetable, which must prioritise quality standards on the basis of a clear rationale, and increasing the pace at which standards are developed is underscored by the relationship between quality standards and the COF. Having a quality standard represents one of only two

[5] Dementia and stroke
[6] Epilepsy (adults) and epilepsy (children)

routes by which it is possible for a condition or condition area to qualify for inclusion in this key accountability framework; the other is having an indicator in the NHS Outcomes Framework.

3.10 In defining the key areas that CCGs must report against in respect of improvement to the NHS CB, the COF will be central in determining the commissioning activities of CCGs. Unless additional channels through which indicators can be integrated into the COF are opened, further delays to the development of neurological quality standards will have a double impact in both denying CCGs access to vital support and guaranteeing that neurology remains outside the formal NHS accountability frameworks for the foreseeable future.

Quality standards and the broader NHS quality, accountability and improvement architecture

3.11 The role of NICE quality standards in supporting commissioners assumes a heightened importance in respect of neurology when considering the broader context of the new NHS quality, accountability and improvement architecture. Throughout these arrangements, neurological conditions are profoundly underrepresented. This approach is particularly concerning given that the recent NAO[7] and PAC[8] reports on services for people with neurological conditions identified a lack of accountability at national and local level as central to the current status of neurological services as delivering poor outcomes for patients and poor value for money.

3.12 Despite neurology accounting for £4.3 billion of NHS spend annually[9] and representing the seventh largest NHS budget spending category, neurology-specific accountability and incentive mechanisms are virtually non-existent under the arrangements due to become operational in April 2013.

3.13 There are no references to neurology in the draft NHS mandate, by which the Secretary of State will hold the NHS CB to account. Of the 60 indicators in the 2012/13 NHS Outcomes Framework, through which the Department of Health will hold the NHS CB accountable, only three are neurology-specific, with one each allocated to stroke, dementia and epilepsy[10]. Similarly, of the 44 indicators NICE has recommended populate the COF, which CCGs will report against to the NHS CB, the 10 neurology specific indicators again relate only to stroke, dementia and epilepsy.

3.14 Consequently, together with the recently announced strategic clinical network (SCN) for mental health, dementia and neurological conditions, NICE quality standards are the second of just two parts of the reformed system that give neurological conditions specific focus and provide CCGs with any support and guidance on how to commission high quality, cost effective and appropriate care for this notoriously complex and historically neglected group of conditions.

3.15 Indeed, the SCN and NICE quality standards represent the only explicit indication under the reformed NHS that CCGs will be the key player in reversing spiralling neurological costs, reducing disproportionate emergency admission rates and driving urgent service improvements in this area. Even Joint Strategic Needs Assessments (JSNAs) on which local commissioning plans will be based routinely omit the vast

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[7] *Service for people with neurological conditions* - National Audit Office, December 2011

[8] *Services for people with neurological conditions* - House of Commons Committee of Public Accounts, Seventy-second report of Session 2010-12, 27 February 2012

[9] Programme Budget Expenditure 2010/11 - Department of Health

[10] In under-19s

majority of neurological conditions due to the chronic shortage of centrally and locally collated neurology data.

3.16 The need to properly equip CCGs to tackle neurology is further emphasised by the generally poor levels of understanding of neurology amongst health and social care professionals, resulting from the complexity and relative rarity of the vast majority of neurological conditions. Despite the clear and significant support needs commissioners will have if they are going cater for the care and support needs of people with neurological conditions, the new system architecture will require that they do so in the absence of:

- a national outcomes strategy for neurological conditions
- a dedicated national neurological advisor to the NHS CB to lead on and coordinate improvements in neurological services
- mandatory accountability and incentive mechanisms
- NICE guidelines, which exist for only a small number of neurological conditions

3.17 In view of this, NICE quality standards, together with the SCN for mental health, dementia and neurological conditions, will need to play a pivotal role in encouraging CCGs to take neurological conditions into proper account in their commissioning plans.

3.18 We do not regard this situation as adequate given the non-mandatory status of quality standards. Additionally, their intended purpose is as one of a range of sources from which commissioning priorities should be determined, alongside JSNAs, Joint Health and Wellbeing Strategies, the COF, national level outcomes strategies and NHS CB commissioning guidance. As these instruments currently give little or no profile to neurological conditions, it would be unrealistic to expect CCGs to give priority in its commissioning decisions to neurology or any other condition area on the basis of quality standards alone.

3.19 The NHS CB and Department of Health need to go further to ensure that due consideration is given to neurological conditions in commissioning decisions, starting by appointing a national clinical advisor for neurology and devising an NHS CB outcomes strategy for neurological conditions.

3.20 We believe that NICE quality standards could play a positive role in the new NHS system architecture but that this potential will only be fulfilled if NICE and the Department of Health rapidly arrive at an agreement on a development timetable, based on robust criteria. From a neurological perspective, quality standards bear a great deal of responsibility for driving service improvements and, as such, their early development and publication is an imperative for patients, the NHS, Government and taxpayers alike.

4. Contact

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