

Response to Equity and Excellence: Liberating the NHS

The Neurological Alliance is pleased to respond to the Coalition Governments white paper Equity and Excellence. More detailed responses will be made to the specific consultation on Commissioning and Outcome Framework. Also, many individual members of the Alliance will be submitting responses with more detailed recommendation relating to their specific patient group.

1. The state of neurological services

- 1.1. Over eight million people in England are living with a neurological condition¹, from epilepsy to motor neurone disease, from ataxia to acquired brain injury. Population aging and its association with a number of neurological conditions, not least dementia, means that this number will grow steadily over the coming decades. Most neurological conditions are chronic or progressive and few have cures.
- 1.2. This need has not been translated into routinely good services and the reforms suggested in the White Paper are an opportunity to deliver improvements in neurology services across the country. If these reforms are to succeed for people with a neurological condition they need to deliver consistently high-quality, cost-effective, integrated health and social care services that will improve clinical outcomes and maximize quality of life.
- 1.3. There is a body of evidence that over the last decade, neurological services have not benefited from the same level of investment or improvement as other clinical areas.
 - The national benchmarking study commissioned by the DH showed, “Nearly half way through the ten-year implementation period of the NSF for Long-term Neurological Conditions, only half of Primary Care Trusts had a written action plan for implementation and very few had carried out their plans”.²
 - User feedback surveys indicates delays in diagnosis, poor access to information, delays in referral to specialist care and lack of consistency in accessing effective rehabilitation, palliative care, social care and support for carers.

2. Putting patients and public first

- 2.1. We strongly support the emphasis on shared decision making with patients and increased choice. However, increasing the personalisation of healthcare needs to be carried out at a pace that is appropriate to all users of the NHS. Many are not equipped to take advantage of this greater flexibility and need advocacy and support. Also, many health care professionals will have limited knowledge of neurological condition, so for shared decision making to work there needs to be significant workforce development, including a culture shift in professional attitudes. The level and accessibility of information to support decision making is also crucial. The voluntary sector has long been a trusted provider of patient information and would like to see this recognised and supported in the forthcoming chapter of the White Paper on information.

¹ Neurological Alliance. *Neuro Numbers*. 2003

² Bernard, Aspinall, Gridley, Parker. *Integrated Services for People with Long-term Neurological Conditions: Evaluation of the Impact of the National Service Framework*. University of York and Social Policy Research Unit. Sept 2010

- 2.2. The Alliance agrees with proposals in the White Paper to develop PROMs as a constructive step forward in measuring outcomes of care. There are no neurology PROMs that are fit for purpose and it is a priority to develop one that will allow patients to give robust, validated feedback on their experiences of services.
- 2.3. We are pleased that the Coalition Government has agreed to uphold the NHS constitution, which set out the rights and responsibilities for patient and staff. The Alliance urges the Coalition Government to widely reinforce these rights at a local level as one of the key mechanisms to demand quality services on the ground. If the vision of holding service providers accountable to patients at a local level is going to be realised, there need to be clearly articulated entitlements for patients to use as a lever to speak out when they are not receiving quality care.

3. Improving healthcare outcomes

- 3.1. The Alliance supports the principles of achieving a world-class health service, focused on outcomes and quality standards. We strongly support the inclusion of patient experience along side mortality, morbidity and safety, as key objectives for the NHS. Most neurological conditions cannot be prevented or cured so optimum health care is about providing the best management of the condition and maximising quality of life. These objectives do not always lend themselves to simple quantitative measures of outcome but require a more patient centred and qualitative approach.
- 3.2. There must be a neurology component included in the Outcomes Framework and NICE quality standards to ensure that there is some focus brought to bear on the specific needs of this large patient group. Experience of the patchy implementation of the NSF for Long-term Neurological Conditions demonstrated that if left to local decision-making, neurology is often not prioritised for local service improvement. Work is underway amongst neurology patient groups and other stakeholder to develop appropriate outcome measures for neurology, which will be included in the response to this section on the consultation.
- 3.3. In establishing more autonomous institutions with greater freedom we feel there needs to be robust arrangement to ensure that these organisations responsibility to patients is maintained, with strong regulation and the setting of robust standards.
- 3.4. We support moves to increase the integration of health and social care. Most people with neurological conditions will require care from both the NHS and local authorities and where the pathway can be successfully joined up across both, there is an improved outcome for the patient. For example, lack of access to secondary preventative care has serious cost implications for service-users once their condition has deteriorated. The All Party Parliamentary Group for Parkinson's Disease Inquiry³ found evidence of significant inequalities in access to aids and equipment, respite care and support for carers – with huge effects on how well people can live with this progressive condition. Similar inequalities were exposed by Epilepsy Action's Time for Change report.⁴
- 3.5. The Alliance welcomes the increase in real terms spending in the NHS but has concerns about cuts to social care budgets and the knock on impact on health services. As most pathways for neurological conditions cross NHS and local authority services frequently, it will be impossible for service cuts in one area not to impact on the other. We call on the Coalition Government to minimise cuts to local authority social care provision.

³ All Party Parliamentary Group for Parkinson's Disease. *Please Mind the Gap: Parkinson's disease services today*. July 2009

⁴ Epilepsy Action. *Time for Change*. January 2009

4. Commissioning

- 4.1. The Alliance believes that proposed changes to commissioning by GP consortia presents some risks to neurology services.
- 4.2. Individually, most neurological conditions are of relatively low prevalence and some are extremely rare. There is therefore a rationale for commissioning neurology services for sufficiently large populations to ensure there is a critical mass of patients to develop pathways of care from diagnosis through to end of life.
- 4.3. Neurological commissioning spans a wide range of services from highly specialised to more generic services. It is complex and challenging. As a result, it is often not done well, leading to patchy and ad hoc services. This in turn leads to poor patient outcomes and unnecessary and costly demands on services.
- 4.4. Added to these challenges, the level of knowledge and expertise among commissions can be a barrier to service improvement. Neurological conditions are not understood in the same detail as other long-term conditions and the number of metrics, tools and guidance that exists to support commissioning is more limited.
- 4.5. GP consortia will cover relatively small population groups and in general GPs will have little expertise in neurology. The Alliance membership is very concerned that over time the variation in the quality of service will increase as commissioning becomes more localised.
- 4.6. In order to mitigate this risk we feel there needs to be:
 - Responsibility for neurology commissioning by the National Commissioning Board
 - Explicit inclusion of neurology measures in the Outcomes Framework.
 - Inclusion of neurology indicators in the Quality Standards under development by NICE.
 - Development of commissioning guidance for GPs. This could be developed by the third sector with support through a Third Sector Investment grant.
 - Explicit inclusion of relevant neurological services within specialised commissioning arrangements.
 - Development programmes for GPs in neurological conditions and good practice in commissioning.
- 4.7. The third sector can and is working to develop the capacity and capability of commissioning in a number of ways. The Alliance supports a network of Regional Alliances that bring together the local neurological community to ensure the patient perspective is reflected in local commissioning decisions. The sector has also developed a wide range of neurology training programmes, tools and guidance and continues to offer its expertise on neurological conditions to the NHS and social care. GP consortia should be urged to look to the voluntary sector for support in their new commissioning role.

5. Autonomy, accountability and democratic legitimacy

- 5.1. The Alliance welcomes the focus on increase accountability to patient and the public. We believe that the NHS Commissioning Board and GP consortia can best involve patients by:
 - Having a significant representation from patient groups on all Health and Wellbeing Boards, GP consortia Boards and the NHS Commissioning Board.
 - Ensuring decisions are open and transparent and can be challenged by patients and patient groups.
 - Explicitly upholding the NHS constitution.

- Giving Health Watch the duty and resource to investigate local provision and commissioning of services when patient groups raise legitimate concerns.

6. About the Neurological Alliance

- 6.1. The Neurological Alliance is the united voice of charities and professional groups in England working to champion the needs of the eight million people living with a neurological condition.
- 6.2. With a membership of around 70 organisations, we collaborate to ensure people have access to high-quality, joined up neurological services and bring about the implementation of national strategies such as the National Service Framework for Long-term Neurological Conditions.