



Consultation on the NHS Commissioning Board Mandate

Neurological Alliance and Association of British Neurologists response overview

Introduction

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. The Neurological Alliance has a very close working partnership with the Association of British Neurologists

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 each person diagnosed has access to high quality, joined up services and information from their first symptoms, throughout their life.

The Neurological Alliance and the Association of British Neurologists welcome the opportunity to contribute to this consultation on the mandate to NHS Commissioning Board (NHS CB). Our response addresses the mandate on a line by line basis, making a series of key recommendations. These are also captured in the summary table below.

Summary of recommendations

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| 1. The NHS Outcomes Framework should include a range of neurology-specific indicators to ensure the NHS CB has a duty to support Clinical Commissioning Groups (CCGs) in respect of improving diagnosis and enhancing outcomes for neurological conditions. |
| 2. Objective 2 should include an explicit reference to complex and less common as well as long term conditions and a requirement for the NHS CB to develop a comprehensive, fully resourced implementation strategy for the Long Term Conditions Outcomes Strategy, including robust accountability measures. |
| 3. Objective 4 ii) should include a reference to recommendations by carers in addition to patients. |
| 4. Objective 6 should relate the stated need for continued improvement in health outcomes to other elements of the health service's quality and incentive architecture, including outcomes strategies and NICE quality standards. |
| 5. Objective 7 should specify a duty to narrow inequalities in access to services, irrespective of where an individual lives and what condition(s) they have, as well as relating to inequalities in health outcomes. |
| 6. Objective 10 should reflect where rights enshrined in the NHS constitution are not being observed or the standard of care is not acceptable, that this will in part be the NHS CB's responsibility as the steward of CCGs and the direct commissioning body for specialised services. |

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| <p>7. Objective 12 should:</p> <ul style="list-style-type: none"> • substitute the term 'enable' with 'realise' in respect of shared decision making • include reference to the need for commissioners to support all people to be involved in decisions about their care and treatment • highlight the need to enhance diagnosis rates, particularly for complex, less common and rare conditions, to ensure that individuals can be part of shared and timely decisions about their care and treatment • require that CCGs collaborate to support people remotely and share expertise where an individuals choice is limited in respect of primary care providers and lead clinicians by dint of the rarity of their condition or seclusion of their residence |
| <p>8. The following key measure should be included against Objective 13:</p> <ul style="list-style-type: none"> • the Board has promoted the value of multidisciplinary team working, including through requiring CCG engagement with strategic clinical networks and clinical networks <p>Additionally, inclusion of the following wording in respect of assessing fragmented care through unnecessary time spent in hospital:</p> <ul style="list-style-type: none"> • 'For example, we will look specifically at unnecessary time spent in hospital by people with dementia <i>and other neurological conditions</i>'. |
| <p>9. The additional key measure should be included against Objective 14:</p> <ul style="list-style-type: none"> • easy and quick access to information upon diagnosis for patients, carers and families, including in relation to relevant support groups, advocacy services and patient representative organisations. |
| <p>10. Objective 16 should include the following points:</p> <ul style="list-style-type: none"> • Working with relevant third sector organisations in developing innovative solutions to tackle identified health challenges. <p>The following key measure should also be included against Objective 16:</p> <ul style="list-style-type: none"> • Evidence of a reduction in variation of experience in the transition from child to adult social and health services. |
| <p>11. Objective 17 should replace the term 'promote' with 'enforce' in relation to access to clinically appropriate drugs and technologies recommended by NICE.</p> <p>The following points should also be included in Objective 17:</p> <ul style="list-style-type: none"> • promotes greater participation in clinical trials • promotes research in respect of rare disease, in part through implementation of the forthcoming UK Rare Disease Plan. |

12. The wording of **Objective 18** should be strengthened in respect of the role of clinical networks and senates to position them as 'key sources of advice and insight, with which commissioners have a duty to engage on an ongoing basis and will be assessed against'

The following points should also be included in Objective 18:

- the Board provides comprehensive guidance in respect of commissioning services for neurological conditions to support CCGs to provide cost efficient and appropriate services for their whole populations
- the Board monitors collaborative arrangements between CCGs to ensure that comprehensive services are provided for people with less common conditions

Section 1: The Strategic Context

The first section of the mandate places a great deal of emphasis on those conditions that are preventable or that affect an ageing population. Whilst these represent a key challenge for the NHS, it is extremely important that conditions that are unpreventable and not acquired through old age are not ignored. The vast majority of neurological conditions fall into this category and are characterised by rarity and complexity.

As the National Audit Office¹ and Public Account Committee² reports on neurological services and the Government's subsequent response³ have indicated, neurology has not been given due priority for too long simply because it has been considered too difficult. It is crucial that, from the outset, the NHS CB ensures that all health problems are addressed regardless of how challenging they are in order to prevent long term avoidable consequences at high financial and societal cost. The mandate must set the tone for the NHS CB accordingly.

The challenges facing the health and social care system

- 1.4** In respect of the urgent and pressing challenges facing the health service, we would urge recognition in the mandate of the need to enable people to remain independent for as long as possible and ensure that people with long term conditions and carers have the highest quality of life possible.
- 1.8** Given that the mandate is a multi-year document but will be reviewed annually, it would be helpful to establish how the different review cycles of mandate and the NHS Outcomes Framework will work. This will be important to ensure that there is not a substantial part of the year where the health services' priorities are not necessarily complementary and are split between two documents.
- 1.9** Greater clarity is required in relation to the circumstances under which the mandate can be changed in-year; details of what would be regarded as an 'exceptional circumstance' would be extremely helpful. Unless this term is well defined, there is a

¹ *Services for people with neurological conditions* - National Audit Office, December 2011

² *Services for people with neurological conditions* - Public Accounts Committee, March 2012

³ Treasury Minute on Public Accounts Committee report on services for people with neurological conditions – April 2012

risk that exceptional circumstances could be cited too frequently, preventing the effective implementation of long term improvement planning.

- 1.12** We support the mandate's affirmation of duty of the NHS CB to promote a comprehensive health service available to all, but would stress the need to state explicitly that this applies regardless of where an individual lives or what their health condition(s) might be.

We also welcome the statement that the NHS CB has a duty to ensure provision of an equitable health service throughout the period of transition to the new health structures and that the Board should be setting the parameters to support the development of clinical commissioning groups (CCGs) and other aspects of the health infrastructure.

Initially, a more prescriptive approach to the development of CCGs will be required by the Board if it is to fulfil its core duties. Until CCGs have matured and developed a strong foundation from which they are able to innovate, there is a genuine risk that many complex and less common condition areas will be overlooked without significant support from the Board as CCGs focus will on prevalent and higher profile disease areas. This potential is considerably increased given the narrow scope of the Commissioning Outcomes Framework (COF) to which CCGs will look for guidance on where to focus their attention.

Where services for less common conditions are not going to be commissioned at a specialised level by the NHS CB, CCGs will need additional support and guidance to enable them to commission appropriate, comprehensive services that are cost effective for their population.

The NHS Commissioning Board as part of the health and social care system

- 1.14 - 1.15** We support the Board's involvement with other organisations and the need for a collaborative approach with shared values and principles. We welcome the mandate's expectation that arm-lengths bodies will work collaboratively; open and effective channels of communication between the component parts of the new system will be crucial from the outset if it is to be responsive and accountable.

Additionally, it is crucial that the mandate specifies patient representative organisations as key partners with which the NHS CB must form enduring relationships. If the rhetoric of patients being at the heart of the NHS is to translate into reality, these organisations will need to be engaged in constructive dialogue with the NHS CB on an ongoing basis. Without making this partnership explicit in the mandate, engagement with patient representative organisations could be regarded as optional for the NHS CB, making the patient voice peripheral as opposed to integral to the Board's operations.

It is concerning that the structure, responsibilities and accountabilities of the Board remain so opaque with just 6 months until the Board becomes fully operational, and where the Department of Health's role begins and ends is far from defined. It will be critical for organisations and individuals to know who is ultimately responsible and to whom they should direct enquiries.

Without such clarity, there is a danger of duplication which will be costly for organisations, a possible point of confusion for individuals and administratively

burdensome for both the Department and the Board. The mandate should at the very least signpost a single source of information where the responsibilities and line of accountability between the Department and the Board are clearly set out. This must not be the Health and Social Care Act 2012, which patients and the public should not be required to negotiate in order to access this vital information.

Section 2: Improving our health and our healthcare

Better healthcare outcomes

2.1 - 2.4 Whilst the foundation of the mandate, which is broadly based around the NHS Outcomes Framework and the COF indicators, will be welcomed by those with an interest in the condition areas that the frameworks focus on, the close relationship between these frameworks and the mandate presents a challenge for neurology.

There is much to be done to improve services for people with neurological conditions, as documented by three recent independent reports⁴, yet of the 44 COF indicators recommended to the NHS CB by NICE, only a very small number relate to neurological conditions⁵. With so much emphasis on the COF in terms of local accountability, if the recommended COF indicators are accepted by the NHS CB, there is an obvious danger that commissioners will focus on the targets set by the COF and consequently not engage directly with the need to improve conditions for the 8 million people with neurological conditions.

We also do not believe that the indicators in the COF and NHS Outcomes Framework adequately 'reflect the challenges that the NHS will face in the future' as there are clear omissions which are known challenges for the NHS in the coming years; neurological conditions provide a conspicuous example.

Whilst we understand that it would be inappropriate to set condition specific targets within the mandate, we believe that categorisation of substantial condition groups is both possible and desirable. This logic is already applied in the mandate to certain areas, specifically mental health, dementia and cancer, and we strongly urge the Department to employ this approach consistently in respect of neurological conditions and other similarly broad areas.

We agree with the mandate's assessment that as the population ages there will be a greater number of people living with long term conditions but would stress that long term conditions must not be regarded exclusively in association with older age. Long term neurological conditions are on a spectrum, with some present at birth and many others commencing at any time during adulthood.

It is therefore important that the mandate acknowledges the diversity of the long term conditions spectrum. With the exception of dementia, mental health and cancer, the mandate gives no profile of the condition areas sitting under this broad umbrella and there is a significant risk that the NHS CB and CCGs will understand and report on progress towards improving the management of long term conditions through the prism of those conditions that are the most common or preventable.

⁴ Local adult neurology services for the next decade - Royal College of Physicians and Association of British Neurologists, June 2011; Services for people with neurological conditions - National Audit Office, December 2011; Services for people with neurological conditions - Public Accounts Committee, March 2012

⁵ Stroke, dementia and epilepsy

In addition to improving the quality of life for people with long term conditions, there needs to be a focus on ensuring that people are accurately diagnosed in a timely manner. Without a diagnosis, people are unable to access the range of services and professionals that they need to be supported, to ensure the highest quality of life possible and to reduce the overall societal and economic burden.

Whilst there is a clear rationale for basing the mandate around the NHS Outcomes Framework, the mandate will inevitably reflect the flaws of this framework, risking the continuation of a history of neglect of certain conditions areas including neurology.

Without reference to key areas that require improvement, which for neurology have been acknowledged by third parties including the National Audit Office (NAO) and Public Accounts Committee (PAC), the mandate is missing a vital opportunity to give direction to the Board and thereby CCGs on tackling difficult areas which will therefore continue to be under prioritised.

RECOMMENDATION 1

The NHS Outcomes Framework should include a range of neurology-specific indicators to ensure the NHS CB has a duty to support CCGs in respect of improving diagnosis and enhancing outcomes for neurological conditions

- 2.5** We welcome the efforts of the mandate to stress the need for better coordination between the NHS, social care and public health. For people with neurological conditions, poor coordination between the NHS and social services is often a cause of unnecessary strain and distress. Effective coordination between specialised services commissioned at national level and those commissioned by CCGs is also vital. Improved coordination would make a much needed improvement the quality of life for all individuals interacting with both health and social care services.
- 2.6** We strongly support the identification of the role that quality nursing plays in improving outcomes but are concerned that no reference is made to the essential contribution made by specialist nurses, who have particular importance for improving the quality of life for people with long term conditions. Specialist nurses can play a vital role in ensuring that people are treated safely and with dignity as they have detailed condition specific knowledge which it would be impossible for all general nursing staff to acquire. By providing a link with the multidisciplinary team and community, ward, department and charge nurses, there can be a better approach to providing specialist nursing care.

Domain 1: Preventing people from dying prematurely

- 2.8** This domain places a great deal of emphasis on cancer; given that the mandate is clear in its desire to avoid taking an individual approach to condition areas, it seems contradictory for cancer to be highlighted specifically in this context, with no explicit mention of other clinical areas, such as cardio vascular disease or stroke, where a reduction in avoidable mortality is achievable.

We are disappointed that the Department's rhetoric on moving away from prioritising specific conditions or condition areas, which has been used as a rationale for the development of the generic Long Term Conditions Outcomes Strategy, is not borne out in the mandate. As suggested above, we recommend that this issue is resolved

through the categorisation of substantial condition groups, such as neurological conditions, which are sufficiently broad to be included in the mandate.

RECOMMENDATION 2

Objective 2 should include an explicit reference to complex and less common as well as long term conditions and a requirement for the NHS CB to develop a comprehensive, fully resourced implementation strategy for the Long Term Conditions Outcomes Strategy, including robust accountability measures.

Domain 2: Enhancing quality of life for people with long-term conditions

2.9 Long term neurological conditions will account for a large proportion of the increasing numbers of people living with a long term condition in the future. For all long term conditions, early and accurate diagnosis enables access to appropriate and timely care and support, enabling individuals to achieve the highest quality of life possible.

However, in common with other complex and less common conditions, the lack of understanding about neurological conditions, the difficulty associated with their management and, in many cases, their rarity results in long delays in diagnosis⁶. Given the necessity of a diagnosis to maintaining quality of life and independence, the mandate must highlight the issue of early and accurate diagnosis to give direction to the NHS CB and, by extension, CCGs on the need to focus due efforts to improve the speed at which diagnosis is achieved.

Domain 3: Helping people to recover from episodes of ill-health or following injury

2.10 - 11 Objective 3 is very important for people with types of sudden onset and fluctuating neurological conditions; following a period of ill health and worsening of symptoms, it is important that people have access to rehabilitation services to ensure that people can recover as quickly as possible, maintain their independence and continue working for as long as possible if their condition allows. In order to ensure that this happens, people need access to a multidisciplinary team with occupational therapy, physiotherapy and social care links so that that they can retain an active life in the work place and/or in the family.

Domain 4: Ensuring that people have a positive experience of care

2.12 - 2.14 This domain and its relevant objectives have failed to capture the important input that family and friends can give of a relative or friend's care in hospital, but also for carers where appropriate. For carers the time that someone is in hospital can be a very difficult period, compounded by additional assessments and forms; possible support is available but this is not always known.

Ensuring that carers have a positive experience of care, are included in conversations and are acknowledged as an important source of information is equally important. Carers' experience of the support and care that they have been given will be able to provide a different perspective which will help the NHS improve where necessary.

⁶ Services for people with neurological conditions - National Audit Office, December 2011

RECOMMENDATION 3

Objective 4 ii) should include a reference to recommendations by carers in addition to patients

Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm

The concern regarding the objectives within this domain is that they might not capture the lower level avoidable harm that occurs within the NHS. Attention to how the information is collated and reported will be needed in order that individual error is not overlooked. We support the recommendation in paragraph 2.17 to explore the creation of a new National Statistic as a possible means of collecting more robust data on patient harm.

Maintaining progress across the Outcomes Framework

2.18 - 2.23 The NHS CB states that 'no particular conditions or patient groups have been singled out, in order to avoid distorting clinical priorities' and that they hope this will allow for flexibility to decide where to focus based on local need and circumstances identified through Joint Strategic Needs Assessments (JSNAs). This approach is not rigidly adhered to, as the mandate shows with specific condition examples.

JSNAs do not always successfully identify local priorities and this is often noted within the neurological community, which rarely see neurology given priority despite the clear need to reflect neurological conditions as such. JSNAs are restricted in terms of effectiveness for neurological conditions by the evidence that is available and collated on neurology locally. This is compounded by the poor collation of neurological data at national level, which is a result of the low priority with which the Department of Health has traditionally regarded neurology.

This under-prioritisation is being perpetuated in the NHS Outcomes Framework, the COF and the draft objectives within the mandate. As such, it is not acceptable to rely on these mechanisms to maintain progress and reduce inequalities as under prioritised areas such as neurology will continue to be side-lined.

The phrase 'to have regard to the need to reduce inequalities both in access to and outcomes of healthcare' does not go far enough to place importance on reducing inequalities. The NHS CB and CCGs need to be driven to reduce inequalities of care and providing an improved outcome for all those who have been under-served by the health service. This includes those with a neurological condition, as acknowledged by Sir David Nicholson in his evidence to the Public Accounts Committee's 2012 inquiry on neurological services⁷.

RECOMMENDATION 4

Objective 6 should relate the stated need for continued improvement in health outcomes to other elements of the health service's quality and incentive architecture, including outcomes strategies and NICE quality standards

⁷ Services for people with neurological conditions - Public Accounts Committee, March 2012

RECOMMENDATION 5

Objective 7 should specify a duty to narrow inequalities in access to services, irrespective of where an individual lives and what condition(s) they have, as well as relating to inequalities in health outcomes

Putting mental health on a par with physical health

2.24 - 2.30 We support the need to put mental health on a par with physical health and we believe that the newly announced strategic clinical network (SCN) for mental health, dementia and neurological conditions will help to ensure better collaboration and cross departmental thinking in these areas. There are often co-morbidities and dual diagnoses across these areas of health and the SCN will help to start to improve the links between mental and physical health.

Promoting good mental health and early intervention for those with long term conditions is very important as well as people affected from a young age.

Objective 9 would be stronger and better placed to improve mental health if it stated that mental health should cut across physical health so that it is entwined within physical health and given the priority that it needs.

Developing the NHS Outcomes Framework

2.32 In addition to the areas listed, complex and less common long term conditions also need further work to develop outcome indicators and how these might be tracked. There is already a large body of indicators for more common conditions but there are many conditions which are less well understood and would benefit from greater focus to track outcomes.

We welcome the suggestion to develop ways of capturing patients' and carers' experiences through patient reported outcome measures. A focus on integration, meaningful involvement in decisions, choice and control would be welcome within the neurological community. However, it must be acknowledged that for many conditions, particularly rare conditions, the choices can be limited and the NHS CB will need to monitor how CCGs and clinicians involve people in decisions and allow them choose what care they receive. There is a risk that this could end up being more tokenistic than meaningful, which would be a missed opportunity.

The NHS Constitution and service performance standards

2.33 - 2.36 We strongly support the importance given to the NHS Constitution and we hope that the forthcoming review will strengthen its content, profile and status within the NHS overall. The Health and Social Care Act has helped ensure that CCGs and the NHS CB give it priority and promote it.

The NHS CB must ensure that the NHS Constitution is implemented and that improvement is made where necessary. The Board needs to take a proactive approach to ensuring that CCGs are providing access to NICE approved treatments and that waiting times are within the guidelines.

Objective 10 needs to reflect that if improvement fails to occur, these rights are not being observed or the standard of care is not acceptable and that this will be, in

part, the NHS CB's responsibility as the steward of CCGs and the direct commissioning body for specialised services.

RECOMMENDATION 6

Objective 10 should reflect where rights enshrined in the NHS constitution are not being observed or the standard of care is not acceptable, that this will in part be the NHS CB's responsibility as the steward of CCGs and the direct commissioning body for specialised services.

Improving health and preventing illness

2.37 - 2.41 It is essential that the NHS CB takes a preventative approach where possible to reduce avoidable illness. We recognise the efforts to do this, but stress the need to extend the interpretation of prevention beyond stopping the onset of a condition altogether to include preventing avoidable deterioration of an existing condition, reducing complications and maintaining mobility and a high quality of life. This is particularly relevant for neurological conditions, the vast majority of which are unpreventable.

This approach needs to apply across the NHS and we welcome the inclusion of carers' health within this objective. However, this is a matter of high priority and we would hope that notable steps are taken prior to 2014.

Section 3: Putting patients first

3.1 - 3.4 The ambition of the mandate that all patients should have the opportunity, information and support to take an active role in decisions is a positive step. We welcome the statement that care plans encompassing healthcare, social care and preventative care should be available to all with long-term health needs, which would be a useful tool to improve integration that would benefit many people with neurological and other complex conditions.

Having a named professional is also a very positive provision; however, more detail about how this would be 'developed and agreed' would be helpful. We would hope that this would go beyond simply having a discussion and would involve developing a written care plan. This is particularly important for people with fluctuating or deteriorating conditions where individuals might not always be able to communicate what they want and may need to rely on carers to follow their agreed care plan.

Securing shared decision making

3.5 - 3.6 We welcome the steps towards shared decision making however we would suggest that the NHS CB and CCGs will need to do more than promote this. Unless there is an active push to enable, ensure and encourage shared decision making, there is a risk that there will be an unequal uptake of the opportunity to have more choice and control, which could in turn produce further inequalities.

The mandate points to the consultation on how to 'give patients more opportunities for choices about their care and treatment all along the patient pathway' however, it should be noted that this consultation focuses on choice of provider and very little focus on treatment; provider choice does not encompass shared decision making and falls short of giving people choice and control over their care.

Provider choice should not be the focus of shared decision making; giving people choice at primary care, diagnosis and specialist care is fine but there are limitations to this due to peoples' often partial knowledge of what is wrong until a diagnosis is given. Getting a diagnosis for rare and even more common neurological conditions is often highly problematic and can take months or even years. Clinicians do not always go into detail of the various possibilities until they have a clearer idea of what these might be.

Having greater choice and control over a primary care provider would be welcome for many people with neurological conditions as this would allow people to access a GP surgery that best suits their needs, for example a GP with a relevant special interest. However, many conditions are so rare that this is not possible and people in rural areas are presented with very limited choice. In these circumstances, 'choice' has very little practical application. Further work needs to be done to encourage improved collaboration between GP surgeries to support people remotely and share expertise.

The choice of a lead clinician is positive but this would mostly benefit people with more common conditions, where many more clinicians would have a special interest. For a large proportion of people with neurological conditions, there will be very limited numbers of clinicians with specific expertise in their condition. We regard the key choice over which people should have control as the treatment that they receive. The choice however, as specified in objective 17, is quite restricted to NICE approved treatments and does not go far enough to enable individuals to understand the full range of treatments available to them.

Overall, there is concern that the language of 'opportunity' to make choices, 'involvement' and 'enabling' falls short of the promise of placing patients in control of their care and at the heart of decisions. Unless the language used is stronger there is a real risk of exacerbating inequalities resulting in only sections of the population being engaged and aware that they can take up the opportunity to have an active choice.

- 3.9** The introduction of Personal Health Budgets would be a welcome development, but this of course depends on the pilots and forthcoming report due to be published in the autumn. The possibility of a joint budget between health and social care represents a step forward, encouraging integration on an individual basis to the benefit of both those in receipt of the budget and their carers. However, the limitations to this is that the mandate states commissioners should offer it 'wherever appropriate' and people will not have a right to ask for a Personal Health Budget for some time, with people receiving continuing healthcare able to ask from 2014.
- 3.10** It is unclear how objective 12 will be measured and what will inform the NHS CB's report on this objective. The measures identified in the annex do not provide sufficient detail on how this will be informed and what the 'evidence of the NHS CB's role' will be. Unless there are clear indicators there is a risk that the measure will not capture the complete picture.

RECOMMENDATION 7

Objective 12 should:

- *substitute the term 'enable' with 'realise' in respect of shared decision making*

- *include reference to the need for commissioners to support **all** people to be involved in decisions about their care and treatment*
- *highlight the need to enhance diagnosis rates, particularly for complex, less common and rare conditions, to ensure that individuals can be part of shared and timely decisions about their care and treatment require that CCGs collaborate to support people remotely and share expertise where an individual's choice is limited in respect of primary care providers and lead clinicians by dint of the rarity of their condition or seclusion of their residence*

Integrating care around patients

3.11 - 3.12 The Neurological Alliance and the Association of British Neurologists support the call for a health care system that is responsive to the needs of individuals, carers and their families and for better integration between health and social care. The lack of integration causes unnecessary stress and anxiety for many people with complex neurological conditions. A more communicative system between mental health, physical health and social care would vastly improve people's quality of life and prevent unnecessary deterioration or dependence.

3.13 We would stress that coordination of care is important for many conditions beyond dementia; by giving one example in the draft mandate of an increasingly common condition affecting older people, there is a risk of enforcing the assumption that social care and the Care and Support White Paper affects only older people. Many people with long term conditions are of a working age or younger and improving the integration of home care and health care is essential to ensure that people retain their independence and avoid unnecessary hospitalisation at all times.

The Care and Support White Paper has been welcomed but does not answer all of the questions surrounding the care and support agenda. The combination of personal budgets and personal health budgets is subject to evaluation and until the framework is published later this year, there is no concrete evidence of how this will work. The timeframe for this development is five years so it does not show how integration will be improved in the short to medium term.

3.14 The paper points to Health and Wellbeing Boards as a mechanism to achieve integration and places the responsibility back with the local health and care systems. This will result in local variation and will depend on the willingness of CCGs and Local Authorities to cooperate and take on NHS CB recommendations. Whilst this is one tool to improve integration, it should not be exclusively relied upon to achieve integration.

3.15 - 3.16 The ideas regarding joint commissioning and integration of care are commendable. However, the language around these goals is not as strong as we would hope. Integration and joint commissioning are not new ideas and have been around for some time yet they are still not a reality. In order to achieve this goal the NHS CB will need to do more than 'promote joint commissioning' or 'encourage' or 'support'.

Without a more proactive and driven objective it is unlikely that integration and joint commissioning will become a reality. The NHS CB and CCGs need to be tasked with achieving change as opposed to simply encouraging it. We welcome the acknowledgment of the challenge dementia represents but it is not solely dementia

that would benefit from integrated care but many neurological conditions and other areas of health.

RECOMMENDATION 8

The following key measure should be included against Objective 13:

- *the Board has promoted the value of multidisciplinary team working, including through requiring CCG engagement with strategic clinical networks and clinical networks*

Additionally, inclusion of the following wording in respect of assessing fragmented care through unnecessary time spent in hospital:

- *'For example, we will look specifically at unnecessary time spent in hospital by people with dementia and other neurological conditions'.*

Improving information

3.17 - 3.18 Providing people with information in order to make decisions and informed choices will be essential. This has been an ambition of successive governments but little detail is provided in the mandate making it difficult to assess how this will succeed where previous attempts have failed.

RECOMMENDATION 9

The additional key measure should be included against Objective 14:

- *easy and quick access to information upon diagnosis for patients, carers and families, including in relation to relevant support groups, advocacy services and patient representative organisations*

Supporting carers

3.19 - 3.21 We welcome the objective to improve the support that carers receive, particularly the provision of breaks. Informal care is provided by many family members of people with neurological conditions and the variation in support they receive needs to be addressed. However, choice and control, particularly relating to breaks is important. A one size fits all approach is not appropriate and individuals should be given choice and control over how they take a break, when, where and if this is with the person they care for or without them.

Information regarding carers and employment would also be a good measure of support and the ability to have a life of their own. The detail in what the evidence will be to assess whether the NHS CB has met this objective is lacking. The commitment is welcome but the detail on how this will be achieved and how it will be measured will need further development and will need to be referenced in the final mandate.

The link between improved access to services and treatments for the individual affected and therefore reducing the need for informal care is not mentioned at all and we would strongly advise that this is acknowledged within the mandate.

Section 4: The broader role of the NHS

- 4.4** We do not feel that the mandate in its current format sufficiently promotes the partnership between the NHS and third sector organisations, which provide essential information, support and advice to service users, carers, the public and professionals. The third sector has a strong track record of developing innovative solutions to tackle health challenges; the neurological sector, for example, has established Neurological Commissioning Support to assist commissioners in providing cost efficient and appropriate neurological services. To incentivise the development of successful relationships between CCGs and the third sector at local level, we would encourage explicit reference to the third sector as a category of local partner.

Supporting children, young people and families

- 4.7 - 4.11** We know that the experience of transition between child and adult health and social care services is variable. The need to ensure that this transition is both a smooth and positive experience must be a key part of the NHS's duties in respect of supporting children, young people and families and we would strongly advise that this is included under this section of the mandate.

Supporting the Armed Forces

- 4.18** Members of the Armed Forces have an increased risk of sustaining a brain injury. In the event of a brain injury, access to appropriate rehabilitation services is essential and we urge that the mandate makes specific reference to rehabilitation services in respect of supporting the Armed Forces.

RECOMMENDATION 10

Objective 16 should include the following points:

- *Working with relevant third sector organisations in developing innovative solutions to tackle identified health challenges*

The following key measure should also be included against Objective 16:

- *Evidence of a reduction in variation of experience in the transition from child to adult social and health services*

Promoting growth, innovation and research

- 4.20 - 4.22** Whilst the UK research base is strong in many areas, this is not reflected in respect of rare diseases where research is underfunded and consequently sporadic.

To support the successful implementation of the forthcoming UK Rare Disease Plan, we believe that the mandate should relate the NHS CB's statutory duty to promote innovation and health research to all condition areas, including rare disease, to ensure that the NHS is addressing the health needs of the whole population.

Key to promoting both research and the dissemination of innovation in the UK and internationally will be the increased participation of patients in clinical trials. Whilst the mandate specifies the need for increased patient participation in research, the key role that clinical trial participation will play needs to be acknowledged to ensure that this element of patient participation receives due focus.

We believe that objective 17 needs further development regarding the NHS CB's role in promoting access to clinically appropriate drugs and technologies recommended by NICE; where drugs and technologies are mandated, the NHS CB's role must be to enforce access.

RECOMMENDATION 11

Objective 17 should replace the term 'promote' with 'enforce' in relation to access to clinically appropriate drugs and technologies promoted by NICE.

The following points should also be included in Objective 17:

- *promotes greater participation in clinical trials*
- *promotes research in respect of rare disease, in part through implementation of the forthcoming UK Rare Disease Plan*

Section 5: Effective Commissioning

Establishing the commissioning landscape

5.1 - 5.11 We are concerned that the COF in its current incarnation is flawed as a means by which to ensure that CCGs achieve improved outcomes on an equitable basis. In light of the framework's limited scope and the generic nature of indicators relating to the majority of long term conditions, it is inevitable that less common condition areas under this umbrella will not be the focus for CCGs and that they will be able to account for progress against these indicators through presentation of information relating to the most prevalent long term conditions.

This situation is likely to be compounded by the fact that other parts of the NHS quality and incentive architecture, such as quality standards, the Quality Outcomes Framework, do not promote CCG engagement with the majority of neurological conditions. As such, it remains unclear how the new commissioning system will be sufficiently supported and guided to deliver effective, comprehensive and equitable services for the whole population.

Accordingly, we would urge that the mandate provides explicit detail (a fuller account) of the accountability framework within which CCGs will work, including their relationship to Local Area Teams, SCNs and Health and Wellbeing Boards. We would also encourage inclusion of a duty on the NHS CB required to develop further accountability mechanisms to ensure that CCGs do not base their commissioning decisions exclusively on what they will be required to report against in the COF. We recommend that the mandate includes an explicit requirement that the NHS CB develops a robust and adequately resourced implementation strategy, including meaningful accountability mechanisms, for the Long Term Conditions Outcomes Strategy.

Regarding objective 18, we are concerned that the language employed in the mandate to describe the role of SCNs needs to be strengthened to reflect their importance in the new system. Given that successful engagement with SCNs will be part of CCG performance assessment, it is clear that their role goes beyond that of being 'highly-valued sources of advice and insight to commissioners'.

RECOMMENDATION 12

The wording of Objective 18 should be strengthened in respect of the role of clinical networks and senates to position them as 'key sources of advice and insight, with which commissioners have a duty to engage on an ongoing basis and will be assessed against'

The following points should also be included in Objective 18:

- the Board provides comprehensive guidance in respect of commissioning services for neurological conditions to support CCGs to provide cost efficient and appropriate services for their whole populations*
- the Board monitors collaborative arrangements between CCGs to ensure that comprehensive services are provided for people with less common conditions*

Redesigning services to ensure high quality care

5.12 - 5.15 Given the mandate's clear delegation of decision making power to the organisations that comprise the new commissioning system, we are unclear why in respect of service redesign changes must meet the four tests set by the Secretary of State. In relation to such a highly politically charged issue, it seems less than desirable that the Secretary of State retains ultimate control in defining the criteria by which reconfiguration decisions are made. We are particularly concerned that test four (consistency with current and prospective need for patient choice) is open to very broad interpretation and that it may be used to block difficult but necessary changes where there is a political advantage to maintaining the status quo.

The Board's own commissioning

5.16 - 5.18 We share the Specialised Healthcare Alliance's concern about the absence of robust arrangements by which the NHS CB will be held to account for specialised services and echo its call for the mandate to explicitly detail the requirements on the NHS CB in respect of its direct commissioning responsibilities. We fully support the mandate's vision for high quality, responsive and value for money specialised services but would develop this further to highlight the need for effective coordination between specialised and non-specialised services to ensure that those interacting with both receive seamless care.

Section 6: Finance and financial management

6.5 Given that the mandate states that the NHS CB will be responsible for allocating the budget for the commissioning of NHS services to prevent any perception of political interference, we would question how this impartiality will be achieved when management of the overall budget remains the responsibility of the Department and therefore 'the NHS CB should share its approach with the Department as it is developed, and should involve the Department at key stages'.