

## **Consultation on the 2013-15 Mandate refresh**

Neurological Alliance response

### **1. Introduction**

We are the only collective voice for more than 80 national and regional brain and spine organisations in England working together to make life better for 10 million people with a neurological condition.

Our vision is to improve the lives of people affected by neurological conditions and work towards their prevention and eradication. 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.

We are members of the Richmond Group and the Specialised Healthcare Alliance; we make reference to both of their responses to this consultation in our own consultation response.

### **2. Response to consultation questions**

#### **Question 1**

**What views do you have on the proposed approach to refreshing the Mandate?**

As there will be no opportunity to comment on the refreshed Mandate itself, we feel that providing only an outline of additions that NHS England will be integrating into the 2013-15 Mandate does not allow those responding to this consultation to provide detailed and meaningful input.

For example, section 3 of the consultation document does not specify the specialities for which consultant led teams will be required to report on the quality of services; as such, it is not possible for respondents to comment on the appropriateness or otherwise of the specialities selected.

We recommend that in future years, the Government puts out a draft version of the mandate for consultation and that this year's approach is either run as a pre-consultation exercise over the summer or dropped altogether.

We support the Government's intention to retain the objectives set out in the Mandate last year. Like the Specialised Healthcare Alliance, we particularly welcome the retention of the objective on ensuring the measurement and publication of data on the quality and value of services commissioned directly by NHS England. We are, however, concerned at the number of additions it proposes to make through the refresh. Without having measured progress against the existing objectives, we appreciate that retiring any would be difficult to justify but warn against overloading the Mandate. Too many objectives will prevent require NHS England to prioritise certain objectives above others, which we do not understand the purpose of the Mandate to be.

It is important that the Government formally establishes a review process for retaining or retiring Mandate objectives and does not, via this refresh or in future versions of the Mandate, load the Mandate with short term objective or any that are not strategic.

## **Question 2**

**What views do you have on assessing NHS England's progress to date against the objectives?**

In this very early period of NHS England's operation, we are not in a position to comment on its progress against the objectives as the Government has not published any form of assessment to date.

The Government's assessments of NHS England's progress will provide a crucial overview of performance, which will allow for condition and condition area specific organisations to contextualise their own assessments.

We call on the Government to confirm the form and regularity of the progress reviews alluded to in the consultation by the end of October 2013, when NHS England will have been operational for over 6 months. These progress reviews will be of particular importance in relation to specialised services and NHS England's other direct commissioning responsibilities; unlike clinical commissioning groups (CCGs), which are held to account annually through the CCG Outcomes Indicator Set, there is no such robust equivalent accountability mechanism in place by which to specifically monitor services directly commissioned NHS England. Formal reviews of NHS England's progress towards the Mandate's objective will go some way to addressing this lack of accountability.

## **Question 3**

**What views do you have on the proposal to help people live well for longer?**

We note that the Government identifies 'primarily...tackling the five big killers but also childhood mortality' as the means by which to avoid an additional 30,000 premature deaths per year by 2020. In committing to this ambitious goal, it is vital that the Government and NHS take into consideration other causes of avoidable death.

For example, epilepsy is in the top ten causes of deaths amenable to intervention in the UK for both men and women (Wheller, Baker, Griffiths et al, 2007). There are over 1,000 epilepsy-related deaths each year in the UK and research suggests that most of these are sudden and unexpected (SUDEP). 400 of 1000 deaths a year could potentially be avoided. Additionally, deaths in people with epilepsy have risen by 31% at a time when mortality from all other causes has fallen (16%) (Ridsdale, Charlton, Ashworth, Richardson and Guilford, May 2011).

The quality, accountability and incentive architecture of the reformed NHS is already heavily orientated towards the big killers and it is important that the health service does not focus resource on these areas to the exclusion of other health conditions. The vast majority of neurological conditions are both unpreventable and long term; the NHS cannot afford to pay less attention to such conditions as their unsuccessful treatment and management has a negative impact on patients, carers

In line with the Richmond Group's response, we question how the Government has arrived at a figure of 10,000 as the proportion of avoidable deaths for which NHS England will be charged with responsibility; does this relate to NHS England's direct commissioning responsibilities alone or does it encompass CCG activities also?

Furthermore, it is not clear how it will be possible to assess where in the system the vital contribution responsible for preventing an avoidable death has been achieved and so attribute an avoidable death to NHS England or any other NHS organisation.

#### **Question 4**

**What views do you have on using the refreshed Mandate to reflect the plans to strengthen A&E services?**

Increasing pressure on A&E services is often the consequence of failings in the rest of the health and social care system. Whilst we recognise that A&E services must be supported to ensure in the short term that they are capable of meeting demand, it is vital that the Mandate takes a long term view and, as such, obligates NHS England to tackle those problems in community based and hospital care that result in avoidable or inappropriate attendance at A&E.

We know that shortcomings in social care play out in the health service and that this is a hugely uneconomic way to run the health and social care systems. The continued squeeze on local authority budgets and consequent cuts to social care services will only worsen this situation to the financial detriment of the health service and will limit the ability of NHS England and the health service as a whole to contribute to the economic recovery.

As the consultation document does not provide a sufficient level of detail on the specifics of the Government's plans to strengthen A&E services to be included in the Mandate, it is not possible for us to be able to say that we support the intention to reflect these plans in the refreshed version. We would recommend, however, that as a strategic document that seeks to take a longer term view, the Government takes the refresh of the Mandate as an opportunity to provide NHS England a much stronger steer on the need to address the issues within the health and social care systems that result in inappropriate attendance at A&E, as opposed to only highlighting its own proposals on how to strengthen A&E.

#### **Question 5**

**What views do you have on the proposal to reflect NHS England's ambition to diagnose and support two-thirds of the estimated number of people with dementia in England?**

As we highlighted in our response to the consultation on the Mandate last year, we welcome the acknowledgment of the challenge dementia represents; as one of the most common neurological conditions, we fully support the Government's focus on improving care and support for people with this condition.

However, we must stress again that the improvement areas for dementia care that the Government is proposing to integrate into the refreshed Mandate, such as appropriate post-diagnosis support, would benefit all neurological and long term conditions. By singling out one condition in the 2013-15 Mandate and giving it even greater prominence in the refresh, the ability of NHS England to focus on long term conditions equitably is significantly undermined.

We would recommend that the Government takes an alternative approach by using the Mandate to highlight a small number of key improvement areas applicable to all or a significant proportion of long term conditions, such as early diagnosis or access to rehabilitation services, to give NHS England a thematic rather than condition specific focus to its work. This will achieve improved outcomes for a far greater number of individuals.

### **Question 6**

What views do you have on updating the Mandate to make it a priority for NHS England to focus on mental health crisis intervention as part of putting mental health on a par with physical health?

We welcome the intention to update the Mandate in this way and support the Richmond Group's response to this question.

### **Question 7**

What views do you have on the proposals to ask NHS England to take forward action around new access and/or waiting time standards for mental health services and IAPT services?

We support the intention to update the mandate in this way and echo the call of the Richmond Group for the Government to go further by challenging NHS England to ensure everyone with a long-term condition has their emotional and psychological wellbeing needs routinely assessed and addressed as necessary as part the ongoing care planning process.

### **Question 8, 9 & 10**

What views do you have on the ambitions and expectations for the vulnerable older people's plan?

What views do you have on how we should achieve our ambitions on the vulnerable older people's plan, particularly on how to strengthen primary care?

How should the ambitions for vulnerable older people be reflected in the refreshed Mandate?

We welcome the development of the vulnerable older people's plan but stress the need for care and support services to be available and improved for vulnerable people of all ages.

We support the Richmond Group's response in relation to this question.

### **Question 11**

What views do you have on updating the Mandate to reflect the Francis Inquiry and the review of Winterbourne View Hospital?

### **Question 12**

What views do you have on updating the objective to reflect NHS England's role in supporting person centred and coordinated care?

We regard patient-centred and coordinated care as crucial for all people with neurological and other complex health conditions. The £3.8 billion pooled health and social care budget has the potential to enhance the delivery of care on this basis, but it would be helpful to know how 'complex needs' will be defined and so understand the number of people who will benefit from the funding available.

We fully support the principle of a wholly integrated approach to health and care but suggest that the measure attached to the Government's ambition for each area moving to this approach by 2018 is too vague to be included in the mandate.

### **Question 13**

What views do you have on updating the existing objective to reflect the pledges in Better health outcomes for children and young people?

#### **Question 14**

What views do you have on updating the existing objective to reflect the challenge for NHS England to introduce the 'friends and family test' to general practice and community and mental health services by the end of December 2014 and the rest of NHS funded services by the end of March 2015?

The 'friends and family test' is capable of providing some insight into experiences of care within the NHS but is a very limited vehicle and as such should not be regarded alone as a sufficient means of gathering patient and carer feedback. We echo the Richmond Group's call for the an objective for NHS England to support the development and implementation much stronger measures of patient experience, including those aimed at ensuring the views of lesser heard and vulnerable groups are captured.

We would also encourage the Government to consider mandating the collation of patient and carer experience data on a uniform basis across health conditions where possible to enable accurate and meaningful comparisons.

Furthermore, we would urge the Government to assess whether the timetable it has applied to the roll out of the 'friends and family test' is realistic; it should of course be ambitious but it is vital that it is also achievable.

#### **Question 15**

What views do you have on these proposals to improve patient safety?

#### **Question 16**

What views do you have on the proposal to update the Mandate for NHS England to work with Monitor towards a fair playing field for providers?

Our ultimate concern is that people with neurological conditions have access to the full range of services they need, when they need them and that these achieve the best outcomes for the individual. A wide range of providers from all sectors provide such services, and we support the commissioning of care from whichever is most appropriate.

Third sector organisations have often been overlooked when it comes to the provision of services; the contribution that so many have to make is strong, evidence based and high quality and should absolutely be considered on a level with NHS and private provider offers.

In pursuit of creating a fair playing field for providers, it is critical that the Government does not mandate action that will unintentionally disrupt existing local commissioning arrangements that are meeting the overarching objective that all services should be based around; specifically, the achievement of person-centred, coordinated care that achieves the best outcomes possible.

#### **Question 17**

What views do you have on the proposal for Government to provide additional leadership on delivery of agreed pre-existing Government commitments?

Without specifying all the pre-existing Government commitments NHS England has agreed to deliver, to which of these additional leadership will be provided and why and what form this leadership will take, this proposal lacks the information necessary for respondents to express a view on it.

**Question 18**

What views do you have on the proposal to update the objective to challenge NHS England to support the NHS to go digital by 2018?

The potential of digital technology to be used for the benefit of patients is very considerable and support plans to link records between primary and secondary care and between the NHS and wider care and support services, which is vital to enabling proper integration. Digital interaction with the health service will not, however, be appropriate for everyone; as the Government will be aware, many individuals, including vulnerable and hard to reach groups, do not have computer access and require alternative means by which to interact with the health service. We support the aspiration to increase the use of digital technology, but advise the Government to make clear in the Mandate its understanding that digital channels should not and cannot be the only means of communication between patients, carers and the NHS.

**Question 19**

What views do you have on the proposal to be more explicit on the expectation around reporting?

The current Mandate's aspiration for the NHS to lead the world in the availability of information about the quality of services is admirable; in representing part of the health community about which so little data and intelligence is formally collated, we are very aware of the problems associated with improving services in its absence.

We cannot, however, comment on the Government's proposal to include details in the refreshed Mandate on reporting on the quality of services at the level of consultant-led teams for a number of specific specialities when these specialities are not specified.

At GP level, we would emphasise the need for patient experience to form part of the assessment of service quality.

**Question 20**

What views do you have on the proposals to update the objective in asking NHS England to support the recovery of the economy where they can make an important contribution?

**Question 21**

What views do you have on the proposals to make better use of resources?