motor neurone disease association

Response to the consultation on NHS England's mandate to 2020

Introduction

i. Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are about 5,000 people living with MND in the UK. A third of people with the disease die within a year of diagnosis, and more than half within two years. There is no cure.

ii. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer led branches and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

iii. In this response, we address questions one to four in the consultation document.

1. Do you agree with our aims for the mandate to NHS England?

i. Since its creation NHS England has emerged as, on the whole, an unaccountable organisation. While the rationale for its existence was always to allow the strategic direction of the NHS to be at arm's length from government, NHS England has a track record of developing and pursuing its own agenda, without being held to account by the Government. The Government's own interventions, such as the push to seven-day working, have seldom dovetailed with either the existing mandate or NHS England's preferred priorities, and the current proposal appears to be to retrofit the mandate to match recent political priorities. Doubtless by the later stages of this multi-year mandate, political priorities will have changed again. NHS England, meanwhile, has not been held to account for its consistently slow delivery, or at times non-delivery, of much of its work. We offer the following comments on the assumption that the Government will persevere with the current approach, despite its lack of success to date, but while we might agree with much of what is proposed in principle, we anticipate that practice will diverge from it substantially.

ii. We agree with many aspects of the headline aims for the mandate, particularly transforming out-of-hospital care, and ensuring services outside hospital settings are more integrated and accessible. It is vital that the Government recognises that transformation of this sort requires up-front investment: without this, service

changes will be chaotic and often amount to the withdrawal of existing services and their replacement by unreformed pre-existing services not designed to meet the new demands that will then be placed on them.

iii. We support the proposal to set the mandate and therefore budget allocations across multiple years, subject to the budget settlement providing sufficient up-front funding to enable the necessary service redesign: these processes necessarily operate over periods of multiple years, so setting aims and funding over a similar timeframe is appropriate.

iv. The Government's aims for the mandate must be equalled by the resources it provides to the NHS to meet those aims. The consultation paper notes that the Government will use the mandate to hold NHS England to account for the delivery of the Five Year Forward View, and that the Government is providing slightly more than the £8 billion identified as necessary in the Five Year Forward View. However, the conditions set out in the Five Year Forward View for that sum being sufficient have not been met: it assumes a properly funded social care system, and that no more demands will be made of the NHS. In reality, the social care system continues to be drastically underfunded (barring any announcement in the forthcoming spending review to address this), and the Government is making increased asks of the NHS with its insistence on a new approach to seven-day working, and possibly further asks arising from the Accelerated Access Review. If the Government does not equip NHS England to meet the terms of the mandate, the mandate may ultimately be used to hold NHS England to account for something it cannot control.

2. Is there anything else we should be considering in producing the mandate to NHS England?

i. The current mandate highlights certain areas as priorities, notably mental health and dementia. We strongly recommend that wheelchair provision be included as a priority area, and that the framework currently being developed by NHS England should be specified as the scale against which the NHS's delivery will be assessed (notwithstanding that the production of this framework is an example of the chronic delay that affects nearly every aspect of NHS England's delivery). Wheelchair services are used by large numbers of people (anywhere between 500,000 and 1,200,000) and can have a substantial bearing both on their quality of life and on other costs to the NHS (for instance by reducing unplanned hospital admissions). Historically, wheelchair services have not enjoyed sufficient funding, and have not been made a priority locally, resulting in provision often being slow and of poor quality. We have raised this matter with the Minister for Disabled People, who in turn has written to the Minister for Community and Social Care on the subject.

ii. We also support the recommendation of the Specialised Healthcare Alliance that an objective should be included to deliver the national service specifications for specialised services. These services amount to £14.7billion of the NHS budget, and the need for consistency in their provision is increasingly pressing in light of the push towards regional devolution of NHS decision-making. Such a substantial aspect of NHS England's work must be reflected in the mandate.

iii. The proposals for the mandate are also silent on end of life care. We particularly recommend that emphasis be placed on improving opportunities for people to die outside hospital: currently nearly half of all deaths occur in a hospital setting, despite this being clinically necessary, or desired by the individual, in far fewer cases. Avoiding unnecessary admission near the end of life and identifying people who are nearing the end of life when they are admitted should be the key elements in any approach to reducing inappropriate deaths in hospital.

iv. Long term conditions (LTCs) should feature earlier and more prominently in the stated rationale: they account for a large proportion of NHS spending, and the necessity of redesigning services arises largely from the growing numbers of people living for longer with one or more LTC.

v. Another striking omission is research: NHS England has produced no clear evidence of success in meeting its existing commitments to improve research in the NHS and patient opportunities to participate in it, nor has it succeeded in publishing a clear strategy for achieving this. A clearer objective should be included, and thought given to intervention if and when NHS England fails to meet it.

3. What views do you have on our overarching objective of improving outcomes and reducing health inequalities, including by using new measures of comparative quality for local CCG populations to complement the national outcomes measures in the NHS Outcomes Framework?

i. We support the objective of improving outcomes and reducing health inequalities, although for as long as neurology is underrepresented in the NHS's Outcomes Framework and related indicator sets this approach cannot be fully successful. We also agree with National Voices' concern that NHS England appears increasingly to be ignoring the Outcomes Framework in favour of other measures and priorities. The Outcomes Framework should either be made more meaningful and enforced, or abandoned in favour of an approach to accountability that will actually assess NHS England's work.

ii. Measures of comparative quality may be useful as a means of helping people to understand the relative performance of different localities, although again this is subject to the indicators chosen representing an adequate spread of disease areas, including neurology and disability equipment. However, the developing range of regional devolution settlements may mean that CCG boundaries are not useful for comparison in all localities.

4. What views do you have on our priorities for the health and care system?

i. In respect of the Government's vision for a seven-day NHS, the commitment to providing a specific named GP responsible for coordinating a person's care will not be of use to people with complex or rare long-term conditions, whose care will often be coordinated by a specialist healthcare professional rather than their GP.

ii. We do not support the inclusion of a requirement to support the NHS to 'live within its means': contrary to the implication of paragraph 3.23, the conditions set out in the Five Year Forward View under which the NHS might be able to achieve £22billion of efficiency savings have not been met by the Government, so

pressing ahead with a drive for large savings in an under-funded system will inevitably result in substantial cuts to services.

iii. We do not support the inclusion of an objective for the NHS to promote economic growth; this is not the job of a health service. We support the inclusion of an objective to harness research and innovation, and to enable new proven treatments to enter regular use quickly. As part of this, however, we would not support a suggestion that access to treatments should be opened up before adequate evidence of their efficacy has been gathered: we have experience of highly promising treatments for MND in fact proving to be substantially harmful, and widespread early access to them would have shortened the survival time of people with MND even further.

Nature of this consultation process

i. We do not believe that this four-week consultation process has been adequate for a matter of this size and importance. The NHS is arguably our highest-profile public service, and has a bearing on the lives of every citizen at some point. This exercise has been short, and narrowly focused on technical policy audiences, rather than the more sustained engagement exercise with wider audiences that would clearly have been appropriate.

ii. Current Cabinet Office Guidance on public consultation, published when the Government abandoned the previous standard of a 12-week public consultation period, states:

The governing principle is proportionality of the type and scale of consultation to the potential impacts of the proposal or decision being taken, and thought should be given to achieving real engagement rather than following bureaucratic process.

iii. It goes on:

Policy makers should think carefully about who needs to be consulted and ensure the consultation captures the full range of stakeholders affected. Information should be disseminated and presented in a way likely to be accessible and useful to the stakeholders with a substantial interest in the subject matter.

iv. We do not believe that the current consultation can be said to have met these criteria.

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