

## **Comment on the draft NHS England Research and Development Strategy**

### **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. Half of people with the disease die within 14 months of diagnosis. 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. Funding and supporting research into MND is one of the core elements of the MND Association's mission. We spend over £2.5million on MND research each year; our current research portfolio consists of projects costing over £8million.

### **NHS England's strategic aims**

- i. While much of the contents of the draft strategy are welcome, we are deeply concerned that it does not set an appropriate strategic direction for NHS England in supporting research, and misses a major opportunity to identify and address, through research, the healthcare challenges that will face the NHS in the future.
- ii. The strategy's vision, and the objectives flowing from it, can be characterised as being concerned with commissioning, economic growth and short-term patient care. All of these considerations of course have a place in the strategy, but it is startling that both the need to improve care for patients and the concept of biomedical research of itself are both effectively absent. Indeed, most biomedical research will not directly produce immediate short-term benefits for patients: these benefits come through only after years, often decades, of work across entire research communities – seldom from one single item of research in isolation. The strategy needs much clearer focus on the nature of research, and also on why it is conducted.
- iii. The challenges that will face the NHS in ten, twenty or fifty years' time will be significantly different from those that face it today. Some of these may be addressed within the strategy as drafted, for instance the pressing need, around

which there is broad policy consensus, to transform services to place more emphasis on prevention and care in the home, and less on inpatient care, in response to demographic changes.

- iv. Other major healthcare challenges that may become apparent in a few decades' time, however, are research challenges now. Age-related neurodegenerative disease represents one such major challenge. An ageing population and progress in treating the traditional "big killers" mean that in future higher proportions of people will develop, and die from, age-related neurodegenerative diseases such as Alzheimer's, Parkinson's and motor neurone disease. These diseases represent a considerable biomedical challenge: understanding the degenerative processes involved is proving highly difficult, slowing them has been achieved so far by only one drug (riluzole, for MND), and halting them, still less reversing them, is currently far beyond our ability.
- v. Age-related neurodegenerative diseases are highly burdensome to the health and care system: MND's effects are rapidly and profoundly disabling, and in up to half of cases it also involves cognitive change, sometimes profound; the effects of dementias and other neurodegenerative diseases are also increasingly recognised in wider political and societal discourses. Any effective research strategy for NHS England must recognise these challenges and plan to meet them: the difference between an NHS that can cope with these challenges, by providing treatments to slow progression and interventions to alleviate symptoms, and one that cannot, will be stark.
- vi. Current work to identify biomarkers for MND will serve as a brief illustration of the research challenges involved, and how NHS England might consider meeting them. Development of effective therapies for any neurodegenerative disease is greatly hampered by a lack of definitive biomarkers. This type of work is long-term and laborious, but nonetheless essential if we are to make inroads into providing earlier diagnosis, predicting the pattern and speed of disease progression within an individual and assessing the potential efficacy of a compound in early stage clinical development. This research is a partnership between patients, clinicians and scientists. We have seen from studies such as BioMOx that people with MND are enthusiastic participants in biomarker research – even when it has little likelihood of helping them.<sup>1</sup> NHS England should make a clear commitment to such partnerships with patients as a vital part of its central strategic mission with regard to research.
- vii. We therefore strongly recommend that a new objective be introduced to the strategy (with an appropriate accompanying line in the vision, and outcome and impact items), as a new Objective One, that sets the aim to identify developing healthcare challenges over the coming five, ten, twenty and fifty years, and prioritise research to address them in respect of prevention, treatments and effective care interventions.
- viii. While it may be NHS England's objective to meet these challenges in terms of delivering patient care, producing the research to enable this is not a matter for

---

<sup>1</sup> BioMOx – Oxford MND Centre <http://www.oxfordmnd.net/research/the-biomox-study>

NHS England alone. The outcomes and impact items for this objective should therefore set out how NHS England will work with partners across the biomedical research landscape. The NHS should be an indispensable resource in linking lab-based biological research with the real-life events occurring in patients, to produce effective and world-leading therapies: NHS England's strategy must set out a clear ambition to harness this great strength in order to drive biomedical research forward over the coming decades.

#### **Further specific comments**

- ix. There are several items within the draft strategy on which we wish to comment additionally.
- x. Under Objective Three, we are pleased to see the firm commitment to continue meeting Excess Treatment Costs. We recommend that this commitment is clearly communicated throughout the NHS: while research funded by the MND Association is often enabled by this arrangement, it can sometimes be the case that individual institutions are reluctant to meet their obligations, or even do not understand that such obligations exist, which can delay and hinder research.
- xi. Also under Objective Three, the capacity of NHS England staff to undertake research is not the key issue: clinician time is, however, a major pinch point for research. Building time for research into all clinicians' contractual arrangements would be a substantial boon to research. This may in turn require work with funding bodies and Health Education England to ensure that the clinicians have the appropriate research skills and that research is available for them to do.
- xii. Under Objective Four, we support the inclusion of patients in work to set priorities, but recommend that the scope of this be broadened to include stakeholders with roles in representing patients and funding research. Not all research funders will do both, but some health charities operate both as patient groups and research funders, including the MND Association. It should be acknowledged that there is not a clear divide between patients on the one hand and funders or researchers on the other: these groups co-exist in sophisticated relationships, and they should be engaged with on that basis, rather than compartmentalised in a way that is likely to result in NHS England benefiting from only partial perspectives.
- xiii. Under Objective Six, we are pleased to see NHS England reiterate its commitment to Commissioning through Evaluation: while we do not expect to see any new drugs for MND eligible to go via this route to patients in the short term, it may be a useful route for some care interventions in the medium term. It is therefore important that NHS England sticks to this commitment, and funds Commissioning through Evaluation appropriately.

**For further information contact:**

John Kell  
Policy Manager  
MND Association  
David Niven House  
10-15 Notre Dame Mews  
Northampton  
NN1 2BG

Tel: 020 72508450

[john.kell@mndassociation.org](mailto:john.kell@mndassociation.org)

January 2014