Simon Stevens, CEO

NHS England

Skipton House

80 London Road

London

SE1 6LH

Dear Mr Stevens

Thank you for arranging for Ninjeri Pandit to reply to my letter raising concerns about the potential harm to patients with a serious long term physical illness, namely myalgic encephalomyelitis (M.E.), consequent on being featured in a guide to be used by the NHS in England that wrongly presently this illness as an example of a ‘functional somatic syndrome’ *i.e.* as a physical manifestation of mental disorder.

Ms Pandit’s response is confined to providing the information that the Joint Commissioning Panel for Mental Health (JCP-MH), which produced the guide, is jointly chaired by the Royal College of Psychiatrists and the Royal College of GPs, and that NHS England is not part of the JCP-MH panel.

I was aware of this when I wrote to you.

I am also aware that NHS England does not directly commission mental health services, and that they are commissioned by clinical commissioning groups of general practitioners.

***Complex service structures and the associated contracting out and fragmentation in today’s NHS in no way justify a hands off approach from the organisation that you are responsible for. The fact remains that, as Chief Executive Officer of NHS England, you have responsibility for ensuring that all commissioning guidance is appropriate and safe***.

NHS England is an executive non-departmental public body, sponsored by the [Department of Health](https://www.gov.uk/government/organisations/department-of-health), and as such it is NHS England that is ultimately accountable for ensuring safe and appropriate practice from the NHS in response to citizens suffering ill health. NHS England is also duty bound to ensure sound use of public funds in terms of NHS healthcare provision. I note also that NHS England commissions the contracts for general practitioners and supports the local health services that they commission.

May I also remind you that a core task of NHS England is to inform the national debate to improve health and care and the NHS England has a duty to fulfil an NHS National Leadership Role. I further note the detail of that national leadership role with the ‘strong belief’ in health and high quality care for all and the NHS England ‘vision’ which “shows that we are getting serious about prevention, identifying and delivering improvements in health care”.

Vision is nothing unless and until translated into practice.

NHS England is supported by legislation in exercising formal powers of direction if satisfied that a CCG is failing - or is at risk of failing - to discharge its functions, having powers to issue a direction notice to a clinical commissioning group in these circumstances. Rather than waiting until you receive specific reports of M.E. patients being harmed following the implementation of this JCP-MH panel document in the NHS, I am requesting some forward thinking and pre-emptive action. Indeed, this is imperative if the reality of your organisation is to match its own rhetoric.

I would like to remind you of UK Government’s continuing acceptance of the World Health Organisation classification of this illness as a neurological disorder. This was most recently reiterated by Lord O’Shaughnessey [Parliamentary Under-Secretary of State, Department of Health] in the House of Lords on the 4th of July [Lords Hansard, beginning column 781]. I would like to ask that NHS England takes due cognisance of this in resolving what is a presently unacceptable state of affairs: both unhelpful - indeed all too often downright harmful - to patients and wasteful of scarce NHS resources.

***My questions regarding the need for change in the NHS approach to patients with myalgic encephalomyelitis (often diagnosed as ‘chronic fatigue syndrome’) remain:***

* Please can you ensure that Commissioners are made aware that the JCP-MH Report, "*Guidance for commissioners of services for people with medically unexplained symptoms*” is wrong to list ‘Chronic Fatigue Syndrome/Myalgic Encephalomyelitis’ as a ‘Functional Somatic Syndrome’?
* Please can you ensure that this pernicious misinformation is taken out of circulation - by the immediate retraction of this document from the NHS and the removal of ‘Chronic Fatigue Syndrome/Myalgic Encephalomyelitis’ from any future editions?
* Please can you reassure me that the misinformation that the JCP-MH has sent to Commissioners will not be used against me to wrongly influence my health, my care, or my entitlements?

***I expect a substantive response that demonstrates that NHS England is taking its statutory duties seriously, and not an attempt to abnegate responsibility.***

Yours sincerely

cc Sir Malcolm Grant, NHS England chair *(address as above)*