Simon Stevens

CEO

NHS England

Skipton House

80 London Road

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Dear Mr Stevens

I expect that you are aware that the Joint Commissioning Panel for Mental Health (JCP-MH) has recently published *‘Guidance for commissioners of services for people with medically unexplained symptoms’*.

I am writing to you to because this publication wrongly includes ‘Chronic Fatigue Syndrome/Myalgic Encephalomyelitis’ and indeed describes this as a ‘Functional Somatic Syndrome’.

As such, commissioners are being misinformed.

The potential for patient misinterpretation, mistreatment and harm is clear and present.

As CEO of NHS England I consider that you have responsibility for ensuring that commissioning guidance is appropriate and safe. NHS England has direct responsibility for commissioning many services, and is responsible for the oversight of the Clinical Commissioning Groups which directly commission others.

Myalgic encephalomyelitis (M.E.) is an organic neurological disease, classified by the WHO under ICD code G93.3. I expect that you are aware that the NHS was mandated to implement ICD-10 (the current version of the ICD) in April of 1995.

There are now over 9,000 peer-reviewed articles describing biomedical pathology, the majority of which use the term ‘chronic fatigue syndrome’ to refer to the patient population. So this illness is not a functional somatic syndrome.

Neither does it fit the description of ‘medically unexplained’ that is used in the publication in question *vis. :*

*The term Medically Unexplained Symptoms (MUS) refers to persistent bodily complaints for which adequate examination does not reveal sufficient explanatory structural or other specified pathology.*

The JCPMH further advise that patients who fit the above description:

*are often subjected to repeated diagnostic investigations, and unnecessary and costly referrals and interventions*

On the contrary, M.E. patients are denied access to the specialist testing that has revealed abnormalities when carried out for research purposes. People with ME are trapped in a cycle where their physical disease is denied.

I am therefore requesting the following action as a matter of urgency:

* 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 Myalgic Encephalomyelitis as a Functional Somatic Disorder?
* 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?

Yours sincerely