

PE1690/HH

Cabinet Secretary for Health and Sport submission of 26 September 2019

Further to my appearance before the Public Petitions Committee on the 24th of January 2019 and my subsequent submission of the 30th of January, I am writing to provide the Committee with a further update on work being undertaken by the Scottish Government and its partners regarding Myalgia Encephalomyelitis (ME).

The Chief Scientist Office (CSO) has met representatives from several ME organisations to consider how academic communities can be supported to increase the level of research on ME. A possibility would be for ME organisations to work with the James Lind Alliance (JLA) to set up a Priority Setting Partnerships (PSP) that would enable patients, carers and clinicians to agree the top 10 priorities for future research on ME. JLA publicises these priorities widely and makes them available for researchers and research funders to access. We have indicated that we would consider a funding proposal to contribute support to the creation of a PSP if this opportunity is pursued.

We are additionally exploring further opportunities to co-fund research projects with ME organisations, including an extension of the existing PhD studentship with the University of Edinburgh led by Professor Ponting. Next month the CSO and the Chief Medical Officer will meet Action for ME and Professor Ponting to learn about progress being made through the current project on biomedical research on ME.

While it is for individual Universities or groups of Universities, in collaboration with potential funders, to decide on the strategic case for a Centre of Excellence in ME Research, we have offered to facilitate discussions if an interest is expressed by these parties.

In terms of raising awareness of ME with healthcare professionals, we are continuing to liaise with NHS Education Scotland (NES) to explore opportunities for this through continuous professional development such as the small group learning module.

With regard to the commitment we made to explore the provision of services and different practices across Scotland, we have spoken to, and met with, stakeholders from the ME community (including people with lived experience and their families, organisations providing support for ME, and clinicians) to consider how this could be achieved.

We have also commissioned two pieces of work: the first is a gathering views exercise led by the Scottish Health Council (SHC) to find out what good care looks like (co-designed with the ME community), the second is an update of the 2011 needs assessment produced by the Scottish Public Health Network (ScotPHN). This will provide a greater understanding of provision available locally within the context of current Scottish Government policies, such as Realistic Medicine, and the vision set out in the Draft National Action Plan for Neurological Conditions that everyone with a neurological condition should be able to access the care and support they need to live well, on their own terms.

Both the SHC exercise and the revised ScotPHN needs assessment are expected to report by early 2020, at which point we will convene a short life working group to consider the findings of this work alongside the publication of the draft guideline by the National Institute for Health and Care Excellence (NICE) that is due in April 2020.

I would be happy to attend another meeting of the Committee next summer to provide an update on actions we plan to take nationally.