

PE1690/BBB

Cabinet Secretary for Health and Sport submission of 25 August 2020

I am writing to provide the Committee with an update on the work underway by the Scottish Government in connection to the above petition.

Since my previous letter of 26 February 2020, we have experienced an unprecedented pandemic that has significantly affected all of us and our public services, with the NHS in Scotland being placed on an emergency footing. As we continue to recover and remobilise safely and incrementally via our route map out of lockdown, we are working closely with partners and service providers across the health and social care system to facilitate consistent national approaches to address clinical priorities and reinstate services paused during lockdown.

This includes still ensuring our NHS is responsive to the presence of the virus and also providing appropriate care and support for those that have been affected, of which we are beginning to understand more about the likely long-term physical and psychological effects. We recognise that research and rehabilitation are critical to our recovery and the long-term sustainability of the health and social care system.

On 13 August we published the Framework for supporting people through Recovery and Rehabilitation during and after the Covid-19 Pandemic. This covers three distinct groups – people who have had Covid-19 and as a result are experiencing ongoing symptoms; those affected by measures taken such as shielding; and those who have seen their existing health issues exacerbated by disruption to their usual care and support.

In resuming services, care and support will feel different to people compared to delivery prior to Covid-19. This is to prevent an unmanageable surge in the virus, ensuring the ongoing safety of the population. By harnessing new technology and techniques that provide faster and more person-centred pathways, the aim is also to enable people to access the right care at the right time in the right place. I chair the Mobilisation Recovery Group, which is enabling a system-wide focus on decisions about resumption of service provision.

I outline the above to explain the constraints, challenges and also opportunities ahead of us, as I am aware the ME/CFS community has expressed concern about the consequences of the pandemic in a number of areas. This includes the impact on progress with actions linked to this petition e.g. to provide specialist services for people with ME/CFS, the continued use of graded exercise therapy (GET) as a treatment (in light of the rehabilitation needs of people with post Covid-19 fatigue) and the potential for an increase in the prevalence of ME/CFS as a result of Covid-19. While it may be a while before there is evidence to definitively confirm/dismiss the latter point, Public Health Scotland is currently undertaking a rapid review to consider and provide a view on this hypothesis. I will provide an update to the petitioner and the committee when its research is concluded.

Much of the work on ME/CFS we started in 2019/20 was paused during the lockdown, which enabled clinicians, the third sector and the Scottish Government to focus on essential work in response to the virus. The delay in publication of the updated NICE guideline to November (draft) and April (final), will impact on timelines to produce NHS Education Scotland small practice learning modules and updates to the Scottish Good Practice Statement (SGPS) on ME/ CFS.

That is why we asked the Scottish Health Technologies Group (SHTG) to undertake a rapid review of GET for ME/CFS and post Covid-19 fatigue. The rapid review noted the validity, applicability and certainty of positive findings around the effectiveness and safety of GET are extensively debated. It advises caution in the use of GET for ME/CFS until the revised NICE guideline and a Cochrane systematic review are published. It also highlighted the recent NICE statement that advises the recommendations in the existing ME/CFS guidance about GET (published 2007) should not be assumed to apply to people with fatigue following Covid-19. We are in the process of updating the SGPS to draw attention to the SHTG rapid review conclusion. Health Boards and GPs will be notified of this update.

Two pieces of work we commissioned in 2019, the gathering views exercise by the Scottish Health Council (SHC) and the health needs assessment by the Scottish Public Health Network (now Public Health Scotland) have also been affected by the lockdown. Fortunately the SHC exercise to gather views from people with ME/CFS about 'what good care looks like' concluded in March 2020. I am pleased to report there was a high response rate from the ME community (450 people provided a response). SHC is presently finalising the report and we expect this to be published in September 2020.

The steering group of the PHS needs assessment exercise will shortly consider the findings of research completed to date with recommendations about the impact of Covid-19 on this exercise. I will keep the committee informed of developments.

In addition, our dialogue with Scottish medical schools will re-commence when the updated NICE guideline is published, although I am pleased to report that we have received replies from medical schools advising how they currently incorporate learning about ME/CFS and welcoming interaction with the third sector and lived experience to support this.

I would like to close by assuring the committee that we continue to work closely with the petitioner, other ME third sector organisations and stakeholders to consider and take account of the needs and wishes of people with ME/CFS, and this includes the re-design of care and support across the whole system following Covid-19. I will write to provide the committee with further updates in due course.

I hope this information is helpful for committee members when they discuss this petition at their meeting on 27 August 2020.

JEANE FREEMAN