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Response to Petition to suspend all trials of graded exercise therapy in children and adults with ME/CFS – March 2017

Thank you for contacting me about clinical trials and Graded Exercise Therapy (GET).

I am aware that the National Institute for Health and Care Excellence (NICE) recommends GET for CFS/ME patients where it is deemed appropriate. However, patients have the right to be involved in decisions about their treatment. There is no one form of treatment to suit every patient and patients should not be forced into treatments they do not want. Rather there must be a collaborative relationship between clinician and patient so that treatment and care take into account personal needs and preferences.

The PACE trial you refer to was the largest ever trial of treatments for the condition and provided evidence that GET is moderately effective when provided alongside specialist medical care. The treatment was found to be safe and in 2013, a follow-up study was published that supported the findings that GET is the most likely to lead to recovery.

NICE considered the PACE trial results when it reviewed the guidelines in 2011 and concluded that the results supported its decision to maintain the existing guidelines. NICE last reviewed the guidance with its stakeholders, including CFS/ME charities, in 2013. The review found no update was required. The full guidelines may be viewed on the NICE website at the following link: www.nice.org.uk/guidance/cg53

I understand that there have been a number of requests for the public release of data from the PACE trial which have been declined. It is my understanding that anonymised data has been made available to independent scientists, as part of normal research collaboration. The release of further data is not deemed responsible as it could breach data protection laws. Nevertheless, further ethical and scientific advice is being sought on how best to provide access to relevant data in a way that balances the rights of participants with the public interest in releasing trial data.

Thank you again for taking the time to contact me.

Kind regards,

Craig Whittaker MP