

Records and Information Compliance Manager
Queen Mary University of London
Mile End Road
London E1 4NS

22nd February 2016

Re: Freedom of Information Act request for release of PACE trial data from QMUL

Dear Sir/Madam,

The Irish ME Trust would like to add its voice to the growing number of UK and international patient representative groups and charities that are calling on Queen Mary University London to release the anonymised PACE data for independent review.

You will be aware the PACE Trial (Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial) has come under intense scrutiny recently by an increasing number of scientists and journalists who have looked at this trial from an unbiased viewpoint.

In October 2015 the Information Commissioners Office ruled in favour of a complainant that had requested the PACE trial data be made available by yourselves, but you have so far refused to comply with this ruling.

The Health Service Executive in the Republic of Ireland tend to follow the UK NICE guidelines in most health cases and this is true also of the care of ME patients. These guidelines recommend CBT and Graded Exercise Therapy as treatments for people with ME. Just recently our Health Minister, in response to a letter from an ME patient, wrote:

"Information on the (HSE) webpage is currently based on the UK NICE guidelines published in 2007. While there may have been recent developments in terms of management of Myalgic Encephalomyelitis, a revised NICE guideline has not as yet been developed/published" Minister of Health, Leo Varadkar, Ireland

You will appreciate that our patient group is therefore directly impacted by UK health policies which are based on the outcomes of the PACE Trial. It is, therefore, incumbent on us to represent our affected population and to add our voice to the call for independent reanalysis of the PACE Trial data.

There is much research now available that demonstrates the dangers of exercise for people with ME. Indeed there is an abundance of anecdotal evidence from patients that would say they have developed a more severe form of ME as a result of GET programmes. We are therefore extremely concerned that our ME patients here in Ireland will continue to be harmed by inappropriate interventions based on the current PACE Trial authors analysis of outcomes.

We very much hope that you will urgently reconsider your decision to appeal the ICO decision and, instead, arrange for the release of the anonymised data for complete independent analysis.

I look forward to your response.

Kind regards

Joan Byrne
Advocacy Officer

c.c. Professor Simon Gaskell, Principal, QMUL