



30 NOVEMBER 2015

New Zealand Health Strategy Update Consultation

New Zealand Health Strategy Team

Ministry of Health

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To whom it may concern,

### Background

We were excited to read the Ministry of Health's (MoH's) Update of the New Zealand Health Strategy.

The documents for consultation were inclusive, relevant, clear and contained ambitious objectives. They would give many a reason to be optimistic about the direction of our healthcare system.

It is encouraging that our services are performing well relative to other OECD countries and that 80% of adults are satisfied with the care they receive. It was also pleasing to hear Ron Dunham, the Chair of DHB CEOs state:

*"We need to understand our population. We need to understand their needs. We need to understand what it takes to make an improvement to the health of the people in our community and we can only do that together"*

We agree.

In the spirit of understanding our population, we would like to highlight the needs of 6,000 Aucklanders who are suffering from a chronic illness. These patients are currently falling through the cracks of New Zealand's healthcare services. Addressing their needs will support the MoH's progress towards the objectives in the New Zealand Health Strategy and we would like to work with you to that end.

### ME/CFS

ME/CFS Support (Auckland) Incorporated is a registered charity established to help Aucklanders suffering from Myalgic Encephalomyelitis (ME/CFS). Around 1/250 New Zealander's suffer from this illness.

ME/CFS is twice as prevalent as Parkinson's and four times as prevalent as Multiple Sclerosis, so it is by no means a not a rare illness. New Zealand research finds that the average patient is in the

bottom 10% of the population on a physical health scale and international research supports this finding, suggesting ME/CFS can be very severe and disabling.

The MoH described that:

*“New Zealand’s health system needs to do better for the populations that do not enjoy the same health as the country as a whole. These include... people with disabilities”*

We believe ME/CFS sufferers fall firmly under this statement and note that MoH's 2012 briefing to the Health Select Committee stated there was "considerable scope for improvement" in regard to education around ME/CFS.

Improving the management of patients is in some ways simple, and many initiatives could be costless. We outline one such initiative below and are eager to engage with the Ministry of Health further on this, and other initiatives that could support the direction outlined in the New Zealand Health Strategy.

### Pathways

The MoH identified the need for "well-designed and integrated pathways" and how "our system needs to be aware of developments and effectively draw on and absorb global ideas and evidence." It is our view that current pathways for ME/CFS are murky and could do more to embrace the latest international evidence. We explain below.

We understand ME/CFS pathways are developed by DHBs and have a significant impact on the nature of care received by patients. Though DHB pathways go by a number of names (for example, Health Pathway, Kupe Navigation, Map of Medicine), we understand that most, in relation to ME/CFS, seem to be informed by the PACE trials.

These trials are the subject of much scrutiny and controversy in the community at present. Whilst this in itself is not a reason to reconsider policy based on these studies, we would like to take this opportunity to make your analysts aware of some recent developments:

- A number of methodical flaws have recently been exposed in the trials. We note the flaws are not trivial and experts believe they undermine the conclusions of the trial. We attach a recent letter to The Lancet which accurately articulates these flaws
- Whilst PACE was a large and well-funded trial, it is only one study out of 9112 published papers on ME/CFS since 1950. A comprehensive literature review was conducted by the USA's Institute of Medicine (IoM) and its finding conflicted with PACE. The National Institute of Health (NIH) commissioned a report in parallel which supported the IoM's conclusions and conflicted with PACE. Given these reviews are the most up-to-date, expert, comprehensive, well-reasoned and independent studies on ME/CFS, we would have thought they would form a much more defensible basis for policy than PACE

- The PACE trials were predicated on the theory that ME/CFS is the result of patient's flawed beliefs about being ill and their illness is perpetuated by deconditioning. This theory is the foundation for the Cognitive Behaviour Therapy and Graded Exercise Therapy treatment approaches employed by DHBs today. We attach research that strongly refutes any notion of a psychological or deconditioning origin to this disease (slides 6-8). We note that expert opinion suggests ME/CFS has a neuro-inflammatory / auto-immune cause
- The authors of the PACE trials have been accused of a violation of the Declaration of Helsinki, by failing to disclose conflicts of interest
- Queen Mary University of London has been reluctant to release the PACE trial's data. In the last month, the UK's Information Commissioner had to order the university to release the trial data under the Freedom of Information Act. If Queen Mary University is unsuccessful in its appeal, the study is likely to undergo even more scrutiny early next year

We consider the IoM guidelines to be a much more robust basis for DHB Health Pathways. We have enclosed a copy of the guidelines for your reference.

Adopting the guidelines is a free initiative that would vastly improve the way patients are diagnosed and managed.

### Thank you

Thank you for considering our response. We are optimistic about the Update to New Zealand's Healthcare Strategy and would like to collaborate with MoH to ensure the needs of ME/CFS sufferers are met in a way that supports your Health Strategy.

Yours sincerely,

[Redacted]

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Enclosures: Letter to the Lancet regarding the PACE trials  
ME/CFS in New Zealand  
The IoM's guide for Clinicians

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