

PRiME - Sending Us Around in Circles

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Five years ago in 2000 I attended what was billed as an Adult Sounding Board Event at the Department of Health in London.

There were over 50 people in attendance and many of those attending handed over letters of support from members of the ME community.

Nearly all of those passing comment via their letters and their views on that day (including the wall of "Post It" notes at the front of the room) all asked for research into cures for ME.

We were told by those presenting this day (including Chris Clark, Val Hockey, Professor Tony Pinching and Dr Charles Shepherd) that the views we all expressed that day would be factored into the CMO's Working Group so that the outcome of this process would represent the views of the ME community.

All told there were many times more than 50 people sharing their views about the need for research into causes and cures for this event that I managed to attend.

At the time I remember saying to Chris Clark that I hoped that the views expressed by all those attending would not end up being "filtered or factored out". In the end this is exactly what did happen.

This wasn't the only event of its kind.

Some weeks before there had been a similar event for Children. This event was also designed to "listen" to patients views and needs and as I understand things there was a very similar response for better healthcare provision, research into the causes and cures for ME.

Of course people at both events were asking for proper investigations and better healthcare provision but none of those attending realised that the NHS was going to provide a string of mental health centres offering CBT and Graded Exercise and nothing else.

I think it would be fair to say that we all felt that any provision would not be dominated by mental health approaches to the exclusion of all others.

At least that is what those of us felt who were stupid not to see what was going on behind the scenes.

I asked the deputy CMO about the prevalence of chronic infections including HHV6 and why testing for such infections was not routine.

I asked this because I knew that others who have a diagnosis of ME have been tested privately and have been found to be positive for chronic infections that are at present not being tested for by the NHS.

No answer was given.

Many people spoke from the audience and many people showed what they wanted in the form of their own personal letters.

Those too severely ill to attend had their views aired on their behalf.

I took a pile of letters from people belonging to this group. Everyone asked for substantial research into the causes of ME and for monies to be spent to find a cure for ME.

It is quite clear now that all those who gave their views were not listened to and their views including mine made absolutely no difference at all to what has in fact actually happened over the last 5 years.

It is my view that those who hosted both Sounding Board Events knew exactly what was going to happen.

They knew exactly where our views would be filed because as we now know, many of those who hosted the Sounding Board Events were already involved with somatoform psychiatry, the string of mental health clinics modelled on Westcare now a part of Action for ME.

Of course we have had 5 years of complaining... 5 years of people presenting all the research that has appeared since the CMO finished off and then published his report to the MRC and such information has fallen down a silent black hole.

We have had 5 years of scientific proof that ME is not a mental health disorder and 5 years of the MRC ignoring such research.

In those 5 years Action for ME has funded some of that research that produced results that Action for ME then fell conspicuously silent upon.

Action for ME then decided to stop funding research altogether and we now know why because every time they funded research it contradicted the mental health agenda of those promoting somatoform disorders, the string of mental health clinics that AfME are involved in creating and the need for CBT and Graded Exercise.

It is now plain to see that there are conflicts of interest all over the place.....

Then - out of absolutely nowhere comes the PRiME Project.

The idea of PRiME is to interview just 50 people this time to find out what patients want for the future.

PRiME is actually repeating what took place 5 years ago albeit in a new format with claimed independence that simply does not stand up when put under close independent scrutiny.

My view is that the outcome of this PRiME project will be identical to what people said five years ago.

But what difference will the result of PRiME actually make bearing in mind that all those who made a great deal of effort to participate in the Adult and Junior Sounding Board Events 5 years ago made no difference whatsoever.

I think the bottom line here is that PRiME can say whatever it likes. It can create a feel good factor but it actually has no power at all to change anything.

Like Action for ME's 1% campaign it can claim anything it likes to create a glossy well meant public relations exercise but it is for the Department of Health and the Medical Research Council to make the actual difference needed to allow researchers to have the funding so that projects to find a cure and a cause can be allowed to proceed.

Thus far these organisations have charted their own blinkered direction and they control the cards, they control the goal posts in secret for what they consider to be "robust" research proposals and they can and have had research bids rejected in secret if such bids go against their underlying somatoform agenda.

Three and a half years on from the publication of the Chief Medical Officer's Report - a report that the psychiatrists refused to sign up to - the MRC has fairly and squarely put its support behind the views of those very same psychiatrists and no one else.

The MRC has been and still are supporting the dominance of a dissenting minority.

Action for ME and others are supporting and collaborating with the MRC.

However, it would be fair to conclude that the MRC does not accord with the views expressed in the CMO's Working Group Report into "CFS/ME".

It would also be fair to conclude that in spite of the empty words of Chris Clark, Action for ME is also supporting the agenda of this dominating dissenting minority.

The fact that the MRC has spent many years denying research funding to non-psychiatric research is yet another example of how the MRC supports the agenda of somatoform psychiatry. The fact that AfME still supports the MRC, Simon Wessely, Michael Sharpe and Peter White speaks volumes for itself.

How far is this going to go?

I understand that ever since the last issue of the WHO International Classification of Diseases was published, Simon Wessely and his colleagues currently pursuing the PACE and FINE trials - paid for by the MRC - have also been attempting to revise the next World Health Organisation International Classification of Diseases to include a new section covering Somatoform Disorders.

The aim of this plan is to formally reclassify "CFS/ME" as a psychiatric somatoform disorder along with other conditions that the psychiatrists deem to be equal or the same including conditions such as Fibromyalgia.

This is why the PACE trial - set up by the MRC - will not distinguish the difference between medical conditions such as what it has chosen to call the heterogeneously grouped disorder "CFS/ME" and Fibromyalgia when it selected patients. This is why the MRC will not follow the view that ICD ME/CFS/PVFS is a neurological disease despite the fact that the Department of Health has to respect the WHO ICD-10 classification that specifically states the opposite.

The MRC are ignoring the rules to promote their own beliefs.

The MRC has chosen to do this because it is sharing the beliefs of Simon Wessely who deems all these conditions to be essentially the same thing... functional psychosomatic disorders.

It would appear that the MRC and Wessely are speaking as one voice. Certainly, when the MRC's Chief Executive Officer, Professor Colin Blakemoore, met the Countess of Mar to discuss this issue he was full of praise for Simon Wessely.

It would appear that the MRC will do all it can to perpetuate the starvation of funding for any research that will conflict with the work of those creating a mental health industry for somatoform disorders.

But in my view they are all building this industry upon failure.

Even when ICD-11 moves "CFS/ME" into a mental health category as it surely will - the underlying flaws and failure of this agenda will remain.

Hard science will and can go on in spite of attempts to starve it of research monies.

The work of Dr Gow and others will go on somewhere - shedding light on the causes of ME and ICD-10 CFS and PVFS.

Eventually, the underlying corruption will be exposed for what it is and those creating a mental health industry around somatoform disorders will be discredited and dealt with in due course.

The prospect of a genetic fingerprint for ME/ICD-CFS proves that the writing is on the wall.

So what of PRiME?

The woman behind PRiME has recently given her spin on what PRiME is all about.

For someone in the media business who knows how to spin a story, she managed to spin the ethos behind the PRiME Project very well indeed.

And I am sure that the outcome of the PRiME Project will look very good.

However, it has no power itself to make any fundamental changes to the all powerful agenda of Somatoform Psychiatry which as we know is supported unequivocally by the Medical Research Council, the Department of Health and the "ME" charity Action for ME.

In my view, PRiME is just another PR exercise along exactly the same lines as the Adult and Junior Sounding Board Events right at the heart of the Department of Health almost 5 year ago today.

People were made to feel that their views were important. We were all made to feel that we were adding an important voice to future plans.

Five years down the line these "events" can now be seen as charades and our views (and there were many more than 50 views) have made no difference at all.

Those who chose to withhold their support from the CMO's Report into "CFS/ME" 3.5 years ago are now at the very heart of the mental health agenda of an MRC that demonstrably believes that the causes of "CFS/ME" are largely psychological and that the solution to those causes is the servicing of such somatoform disorders with CBT and Graded Exercise.

We are being sent around in circles and in my view PRiME is just another circle that will not make a difference no matter how well intentioned the views of the participants taking roles in this project.

Many of those choosing to believe the spin of Vivienne Parry... look at the facts of the past and the present and look at the prospects for the future built on the actions of the here and now.

Yours sincerely,

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MEActionUK - it does exactly what it says on the tin

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