

Politically-modified Research?

Eileen Marshall Margaret Williams 25th June 2005

On 22nd June 2005 Laurie Taylor presented a programme called "Thinking Allowed" on the UK's Radio 4, one of a series of programmes in which contributors discuss topical items coming out of the academic and research worlds. Taylor ended that particular programme with an explosion: "...the last word on methodology, and the importance of valid and reliable empirical work, must go to the anonymous political insider who recently characterised the present Government's approach to research in the following manner: **it is not, he said, so much evidence-based policy-making as policy-based evidence-making**". Never was there a truer word, as the ME community knows to its considerable cost: it has been saying so for many years but has been systematically denigrated and ignored, so it is refreshing to hear this acknowledged and confirmed in such precise terms on the BBC.

That quotation is momentous because it exactly encapsulates the reality: forces intent on "eradicating" ME (and those few medical stalwarts who support them) are at work that are beyond belief. Physicians who genuinely try to help those with ME are themselves victimised, in some cases being reported to the General Medical Council (as, for example, Dr Gordon Skinner, who is to appear before the GMC on Wednesday 29th June 2005 over his treatment of thyroid problems in some patients with ME, a problem whose existence certain UK "experts" refuse to acknowledge).

This "policy-based evidence-making" has now reached such an extent that it has been likened to a cancerous metastatic spread (Stephen Ralph, 25th June 2005: <http://health.groups.yahoo.com/group/MEActionUK/>). There could hardly be a better analogy: metastatic spread takes hold by replicating itself until it eventually dominates and overwhelms, just as the unsubstantiated views about ME of the "Wessely School" psychiatrists have spread throughout the medical profession, the media (perhaps through the activities of the Science Media Centre – see below), Government, and even some of the patients' support organisations, notably Action for ME and the local groups that support it.

It will be recalled by the ME community that after publication of the Joint Royal Colleges' Report on CFS in 1996 of which Professor Simon Wessely was the prime mover (CR54, published by the RCP) -- a report that was internationally condemned for its extreme psychiatric bias -- the Editor of the Lancet, Richard Horton, courageously spoke out against it, saying on the record: "The college representatives interpreted every piece of evidence pointing to a biological cause in a negative light. Medical paternalism seems alive and well in Britain today" (Why doctors are failing ME sufferers. Dr Richard Horton. Observer Life, 23 March 1997).

Horton has also made a stand against hormone replacement therapy, and under his editorship the Lancet published the Arpad Pusztai paper that warned against genetically modified foods, and it also published the 1998 Wakefield paper that lifted the lid on a potential link between the MMR triple vaccine and autism. Although last year the Lancet partially retracted the Wakefield paper, Horton remains critical of the atrocious handling of the MMR situation by Government authorities.

It will be recalled that Horton has won plaudits for his scrutiny of the pharmaceutical industry and that his stance has made enemies. More than once, Horton has been targeted for his principles, the

latest onslaught being on 18th June 2005 when he was the object of a major vitriolic attack from establishment scientists in The Times, which carried banner headlines that proclaimed “Scaremongering’ Lancet accused of causing harm to health and wasting millions”. The signatories, thirty Fellows of the Royal Society, accused Horton of “desperate headline-seeking over sound science, to the detriment of human health”, and of a disregard of a balanced assessment of the best evidence. Clearly there seems to be an orchestrated attack on Horton.

Of interest to the ME community is that one of the 30 signatories is neuroscientist Dame Nancy Rothwell.

It was the same Professor Nancy Rothwell who, following publication in January 2002 of the report of the Chief Medical Officer’s Working Group, chaired the Medical Research Council’s Research Advisory Group (RAG) on the direction of future research into “CFS/ME” about which there was so much public unease, not least because her advisory group chose not only to flout but to ignore entirely the elementary rules of procedure to which adherence is *de rigueur* except, apparently, in the case of ME: it was the RAG’s deliberate policy not to consider any of the existing published medical literature that indicates unequivocal organic, multi-system dysfunction in ME, with the inevitable and possibly intentional result that its conclusions could not sit squarely on the foundation of existing knowledge about ME. By proceeding as if this substantive body of mainstream knowledge did not exist, Professor Rothwell’s group laid itself open to suspicions of frank intellectual dishonesty.

Of further significance to the ME community is the fact that, linked to the attack on Horton, the same edition of The Times carried an item by Tracey Brown that extolled the virtues of the peer-review system in the protection of the public (“Review by peers is vital to ensure accurate science”). In her article, attention was drawn to the need of a growing audience that is hungry for reports of new research; she also pointed out that many thousands of research results published each year turn out to be flawed, about which Ms Brown commented: “Usually, it does not matter (as) flawed work is quickly left behind”. A notable concern is that this article promoted a link to a document authored by Ms Brown called “Peer Review and the Acceptance of New Scientific Ideas” (available free on line at www.senseaboutscience.org).

Here things become interesting, because Ms Brown turns out to be a member of a Working Party convened in November 2002 by an organisation called Sense about Science that proclaims (and is apparently designed) to equip the public with an “understanding” of peer-review, especially on issues of MMR and autism, genetically modified crops, fluoridation and mobile phones in relation to children’s health. In other words, it seems that its aim is to “educate” the public to accept industry’s agenda, although the message is nicely gift-wrapped: “an understanding of peer review might help the public to weigh the relative merits of different research claims”.

The ME community may like to know that apart from Tracey Brown, other members of the Sense about Science Working Group include Professor Colin Blakemore, currently Chief Executive of the MRC that is supporting and funding the psychiatric PACE trials on “CFS/ME” and Fiona Fox, Director of the Science Media Centre upon whose Board Vivienne Parry of the PRIME project sits and whose Science Advisory Panel includes Professor Simon Wessely.

The Science Media Centre itself states: “the team at the SMC is guided by a Science Advisory Panel and a Board”, which would seem to indicate a close working liaison between them, even though Vivienne Parry is on record (Co-Cure, 17th June 2005) denying that she has worked with Wessely and claiming that she has never even met him (for information about the SMC, see

<http://www.sciencemediacentre.org/downloads/consultationreport.pdf>).

The malign influence of financial conflicts of interest in science and medicine are increasingly being exposed and as a consequence, public distrust in medicine has become acute. As Vivienne Parry states in her Co-Cure post, the Science Media Centre is used daily by all the national newspapers and the electronic media. The role of the Science Media Centre seems to be to overturn such public distrust by promoting science (validated by peer-review, of course) as entirely beneficial to human health and well-being.

However, the public needs to be aware that the Science Media Centre is funded by pharmaceutical companies and Fiona Fox has used it to promote the views of industry and to launch fierce attacks against those who question them.

Perhaps surprisingly, the Royal College of Physicians is a sponsor of the Science Media Centre, although perhaps it is not so surprising when one knows that a Past-President of the RCP, Professor Sir George Alberti, also sits with Wessely on the SMC’s Science Advisory Panel. One recalls the many exchanges of correspondence about the ME situation with Professor Alberti during his presidency of the RCP and one now realises why they were all to no avail: even though at the time of these exchanges of correspondence the Science Media Centre was not in existence, the same underlying policy strategy clearly existed.

The SMC operates like a newsroom and claims to offer a specialist resource to science press officers, providing journalists with pre-digested nuggets of scientific information that conform to “policy”.

In its efforts to control the research information that the public should consume, the SMC has taken on key roles in the infrastructure of public communication used by the science and medical establishment and it runs a range of activities, including “media-training”. Without doubt, Simon Wessely seems to be involved with the wider activities of the SMC and is on record as stating: “**We need to defend scientific expertise as a basis for sound policy decisions**” and, together with Lucy Thorpe and her colleagues at Radio 5 Live, he urged SMC staff to find “members of the public to speak out for science when a science story hits the headlines”, whilst Tony Gilland, Science Specialist at the Institute of Ideas, argues that scientists must mount a more aggressive defence of expertise or risk losing more authority in society. Is this because members of the public must never be permitted to question the supreme authority of scientists about disorders such as ME, perhaps? Is it all about State control?

The SMC’s links to the web magazine ‘spiked’ are on record; ‘spiked’ health writer is Dr Mike Fitzpatrick, well-known for promoting the views of Professor Simon Wessely about ME and for his televised attacks upon Dr Andrew Wakefield about a potential MMR/autism connection; for example, when the Chief Medical Officer, Professor Sir Liam Donaldson, went on record on 11th January 2002 about “CFS/ME”, Fitzpatrick publicly derided him and wrote scathingly: “The CFS/ME compromise reflects a surrender of medical authority to irrationality. The scale of this

capitulation is apparent when Professor Donaldson claims that CFS/ME should be classified together with conditions such as multiple sclerosis and motor neurone disease” (see The Mental Health Movement: Persecution of Patients? A consideration of the role of Professor Simon Wessely and other members of the “Wessely School” in the perception of ME in the UK, available online at http://www.meactionuk.org.uk/SELECT_CTTEE_FINAL_VERSION.htm).

Given the power and influence of such a media machine as the Science Media Centre, is it surprising that the long-established values of clinical observation in medicine and the voices of patients themselves are crushed, since they cannot hope to conform to industry-backed SMC “policy”?

Metastatic spread is lethal in all situations but just two illustrations of its effect upon those with ME are provided here:

1. the Minutes of a meeting of a group called “Evidence-based Commissioning Collaboration Steering Group” held on 15th November 2004 about ME/CFS in Rotherham discuss a report prepared on behalf of the Institute of Health Sciences and Public Health Research, University of Leeds, that purported to summarise “current guidance and a holding position pending the preparation of NICE guidelines due for issue in January 2006”; it is tragic that the ensuing discussion included the point submitted by Ms Edwards that “CFS/ME was not a disease as such”. Such an assertion is wrong both in fact and in law. It is also troubling that in the same document, Mark Adams, Clinical Network Lead for CFS/ME for South Yorkshire and North Derbyshire, comments about the report: “The content and conclusions of the report is in line with my understanding of the literature on this subject. I agree with the report’s recommendations for future research focus”. It is even more troubling that the approved actions include the addition to the references of “Professor Simon Wessely’s book” (see http://www.trentfocus.org.uk/Evidence-basedCommissioningCollaboration/CFS%20Final%20Report%2022_11_04.pdf)

2. the struggles of people with ME for rightful benefits continue unabated and look likely to become even more difficult: a post on Co-Cure on 20th June 2005 by Dr Charles Shepherd, Medical Adviser to the ME Association, records that the MEA rejects the new Department of Work and Pensions benefit guidance on ME/CFS and considers it to be unacceptable. This new guidance will replace that which is contained in the current version of the Disability Handbook about decision-making for claims involving ME. Dr Shepherd states that the new guidance contains far too much biased opinion presented as fact; that it contains statements that indicate poor understanding of certain aspects of ME, especially in relation to the severely affected; that it fails to take note of key aspects of the Chief Medical Officer’s Working Group report of January 2002, and that the guidance indicates that inappropriate illness beliefs are far more important than any underlying disease process.

It must be said once again that “Wessely School” psychiatrists walked out of the Chief Medical Officer’s Working Group and did not endorse the final report of January 2002, yet despite this, it is now the very same psychiatrists who are being awarded massive funding to do what they wanted the CMO’s report to recommend -- which it did not – and who are calling all the shots in the new Government-funded Centres.

Such continued refusal to heed the published evidence of biomedical pathology in ME, with the concomitant denial of investigation and appropriate medical care, must surely amount to an abuse

of ME sufferers' human rights, not least the right to life itself, which most severely affected ME sufferers barely attain.

As Mrs DM Jones wrote so accurately in a letter (not published, of course) to the Editor of The Times in response to the highly critical article about Richard Horton: "We need more honest scientists and editors like Dr Horton to redress the prevailing huge imbalance between the over-bearing influence of the (pharmaceutical) industry in collusion with regulatory and governmental authorities compared to the real interests of patients". Indeed so.

Finally, it is noted that in The Guardian (Why didn't they spot the flaws? 21st June 2005) in an article about Professor Sir Roy Meadow's flawed evidence in high-profile cases of sudden infant death which he ascribed to murder (for which mothers were wrongly imprisoned and for which he is now appearing before the General Medical Council), Clare Dyer quoted a telling comment by Sir Alan Craft, President of the Royal College of Paediatrics and Child Health: unsurprisingly, he was supporting paediatricians and seemed to be pointing a finger at the lawyers for the wrong convictions of people like Sally Clark, claiming that lawyers should examine expert witnesses with sufficient rigour. What Sir Alan actually said was: **"the judiciary should know that they have actually got to question where expert witnesses get their opinions from"**.

If only someone with sufficient influence would question where "Wessely School" psychiatrists get their opinions from. If this were to happen, then the rampant metastatic spread of their unproven beliefs would soon stop because their opinions are not -- and cannot be -- based on biomedical evidence. But then, "policy-based evidence" is not required to be based on biomedical evidence and that, of course, is its value to Government.