

AIRA Inc

**Allergies & Intolerant Reactions Association
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MCS Report,
NICNAS,
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AIRA was formed in Canberra in the early 1980s to provide individual support and advocacy as well as systemic advocacy for people with allergies and intolerant reactions. This includes those people now identified as suffering from multiple chemical sensitivities (MCS).

We greatly welcome the commitment of the Australian Department of Health and Ageing (DoHA), through the Office of Chemical Safety (OCS) and the National Industrial Chemicals Notification and Assessment Scheme (NICNAS), to prepare a scientific review of MCS.

We have had the opportunity to consider submissions provided to the review by Prof Martin Pall, AESSRA, ASEHA and the South Australian task force on multiple chemical sensitivities. We support and endorse these submissions as they give voice and life to many of our concerns about the current document.

Our **major concerns** are that the current document has many references to psychological mechanisms as being causative or prolonging factors in MCS rather than only possibly being contributors. It mostly does not admit the value of physiological treatment and management of MCS. Both positions, if accepted as valid, would cause great harm to people with MCS. It is not in Australia's interest to allow them to prevail; the emotional, physical and financial costs are too great.

The clinical review included speaking with four advocacy groups and three MCS sufferers. The **patient perspective** was therefore considered relevant to the clinical picture and should be able to be addressed in submissions. Community input to scientific research (and presumably therefore to reviews of research) was described as follows in the CHF and NHMRC statement on consumer and community participation in health and medical research:

“As the users of health and medical services, consumers can provide valuable input to health and medical research. If such research is to continue to provide high quality outcomes, it is important that consumer involvement in research and its ongoing development is facilitated. This includes participation by consumers as equal partners in the development of research goals, questions, strategies, methodologies and information dissemination.

Research methods and results that are open to informed public scrutiny and debate also help to ensure the integrity of research and accountability to the community for the

quality of the research.” (National Health and Medical Research Council (Australia) & Consumers' Health Forum of Australia. 2002)

We therefore urge the review team to give serious consideration to the concerns raised by consumers, both about how the lived experiences of many with MCS may differ from some of the research evidence and also about the significance for our lives of the conclusions the review is working towards.

An individual can make a decision about what they eat and what environmental exposures they have in their own home, although these decisions may have significant financial costs. What they can't do is ensure that the environment outside of their home is safe for them, where they may wish to shop, work, study, receive medical treatment or participate in community life. That is why this review is so critical for people with MCS. If it concludes that the condition is psychological then there will be little willingness to improve the safety of these environments for people with MCS, not allowing them to **access** them in the same way that other people with disabilities have the right to. That would exacerbate the significant social exclusion commonly experienced by those with MCS.

We believe that due weight should be given to evidence which supports **physiological bases** and evidence which counters psychological bases. Our view is that there is already adequate evidence to conclude that there is a physiological basis to MCS and that people with MCS may have psychological symptoms caused by both the stress of the condition and by some specific triggers.

Medicine has a long history of declaring unexplained illnesses as **psychological**, only to have them proven later to be of physiological origin, for example Multiple Sclerosis, ulcers and AIDS. In addition, in our time, there are powerful influences with vested interests seeking to deny the physiological validity of MCS including insurers and the chemical and pharmaceutical industries.

Not only is there an overlap of symptoms between MCS and the conditions variously known as ME, ME/CFS and CFS/ME, there is also an overlap of **public campaigns** to perceive them as psychological in origin.

In mid-February 2009, the UK High Court received evidence on a **Judicial Review** of the NICE guideline on ME/CFS, as reported by the BBC <<http://news.bbc.co.uk/1/hi/health/7881116.stm>>. At the time of writing, the decision had not been brought down. However, whether or not the claimants met the burden of proof, the fact that the High Court considered that there was a basis for considering a judicial review should focus the attention of future policy makers to the importance of good practices. The judicial review turns on the processes for producing the guidelines, including weight given to particular evidence and the possibility of conflicts of interest.

There is also an ongoing **debate in scientific journals** as to the robustness of published research, including with regard to conflicts of interest, as reflected in the editorial of PLoS Medicine ('An Unbiased Scientific Record Should Be Everyone's Agenda' 2009).

We encourage the review team to be mindful of these issues as they continue their work.

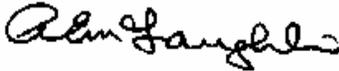
We are also keen to see recognition for **support management strategies** such as avoidance of chemicals in addition to any relevant therapeutic agents such as nutrients.

We consider that people who already know they have MCS are providing our community with an early warning signal of the myriad harmful influences in the man-made environment that are affecting many more people now and will be into the future. It took a long while for the community to accept that asbestos and tobacco were harmful. We should learn from that and accelerate the research into the use of pesticides, herbicides, volatile organic chemicals etc. We urge OCS and NICNAS to pursue a **precautionary approach** to licensing and regulation.

There is a risk that if the only outcome of this review is a commitment to a longitudinal study or other research, then the recognition of MCS as a physiological condition requiring recognition, appropriate management, treatment and access accommodations may be deferred. We therefore seek that the review considers **all** relevant current research and addresses these issues now rather than deferring them.

We look forward to commenting on a revised version.

Regards



President

REFERENCES

- National Health and Medical Research Council (Australia) & Consumers' Health Forum of Australia. 2002, *Statement on consumer and community participation in health and medical research*, The Council, Canberra, accessed 8 February 2009, <<http://www.health.gov.au/nhmrc/publications/pdf/r22.pdf>>.
- 'An Unbiased Scientific Record Should Be Everyone's Agenda', 2009, *PLoS MEDICINE*, vol. 6, no. 2, p. e38, accessed 25 February 2009, <http://medicine.plosjournals.org/perlserv/?request=get-pdf&file=10.1371_journal.pmed.1000038-L.pdf>.