

**ALEXA MCCLAUGHLIN**  
**6A Gynea Street**  
**Narrabundah ACT 2604**

*Phone & Fax* 02 6260 7722  
*Mobile* 0419 431 941  
*Email* alexa@pcug.org.au

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## **SUBMISSION ON THE MCS REVIEW REPORT**

I am an individual who has lived with chemical sensitivities for about 35 years, since the age of 24, well before there was any media coverage of such issues. I have been aware of this review for some years and participated in the consumer meeting with OCS/NICNAS at the end of October 2008, representing AIRA Inc (Allergies and Intolerant Reactions Association).

AIRA is providing a submission on the content of the review document. In this submission, I am commenting on the **process of the review**.

I am very concerned that you had early meetings with **clinicians and researchers** and have not disclosed who they were. It is essential for transparency and accountability that we know who has provided input and what it was.

I urge that that information be put into the review report.

I don't understand how allowing **consumer input** could (as was claimed at the October meeting) give the impression of "hijacking by consumers". Consumers are clearly stakeholders in this matter and offering a four-hour meeting at almost the end of the process was much less than should have been provided prior to public consultation. Failing to take notes at the meeting had the effect that many verbal promises seem to have disappeared since.

Officials agreed at the meeting to modify the emphasis on **psychological approaches**. They did so fairly effectively in the executive summary but failed to carry them through to the underlying text. It is hard to know whether this was "stuff up or conspiracy". For anybody reading all of the report, the psychological emphasis remains palpable.

There was also a commitment to widening the **scope of comments** to be accepted. The changes to the accompanying documents did not really reflect this.

I seek that material on broader questions be seriously considered, because much wider material IS relevant.

I appreciate the **extension** given me for these submissions, but remain concerned that the general submission period was very brief, especially in terms of Australian input which would be constrained by the summer holidays. Some potential contributors unable to meet the deadline may not have sought extensions.

Most importantly, officials agreed to a **further round** of comment, but no advice of this was provided on the website and informal advice is that if it happens it may be a very brief period for comments. I expect that the next version, if it properly reflects the information/evidence provided in this round of submissions, will be a very different document. It will therefore require another significant period for consideration by stakeholders. It would be so much better if any flaws are identified before you publish a final document rather than afterwards.

I seek that there be a further round of comment with an adequate consultation period.

There was also a commitment to **publish submissions online**. I recognise that some people may submit private information in order to give you a flavour of our lived experience. Should they not wish that to be made public, I support that. It is on the other hand, I really want to know what is being provided to you as a submission by organisations.

I therefore urge you to honour the commitment made to us that submissions would be published, allowing individual's privacy if required. Since there was no advice on the website that submissions would be published, you would need to raise this with/for each submission.

I am dismayed that **Dr Pall's submission** was not read in advance of the October meeting. I supplied it weeks earlier because he had clearly (but much more elegantly) expressed concerns that consumers have around the evidence. His brief submission would have enabled the officials to get a handle on our concerns to save us saying it all again at the short meeting. When I found out later that it had not been read, it made me question whether the meeting was just a box to be ticked rather than a genuine engagement.

I understand that it is the policy of the Australian Human Rights Commission that consultation documents be provided in **accessible** text form such as a Word document. The refusal to do so this time, despite a commitment from the OCS, concerns me greatly.

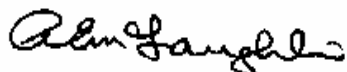
I seek that further documents be provided in a suitable form.

I am grateful for the submissions which detail concerns about particular pieces of evidence which are either misrepresented or missing. I had hoped to do an analysis of the **logical flow** of arguments in the report but was unable to, due to ill health. My impression is that conclusions are often not supported by the evidence quoted or even sometimes there is no evidence quoted. I encourage you to ensure that the next version is logically consistent. In particular, I consider that there is confusion between the terms toxicity and chemical sensitivity.

As I said at the meeting, this draft was of better quality than the final CFS guidelines in terms of mentioning a range of evidence. Nevertheless, it appeared to uncritically accept the "psychological" evidence and not look hard enough for the "physiological" evidence. This is not scientifically **rigorous**. Asking for further information/evidence with the consultation was better than nothing but failed to recognise that just publishing an inadequate review has the effect of reinforcing those views in the minds of many readers in the meantime and they may not read subsequently differing positions.

If the report is not **improved**, it may unjustifiably condemn people with MCS to harassment, vilification and lack of access to many of the elements of life other people take granted. This review is not just another "piece of work", as it may seem to officials, it is the basis for our future lives.

Regards

A handwritten signature in black ink, appearing to read "Alan Fingleton". The signature is written in a cursive, slightly slanted style.