Response to ‘A survey of suppression of public health information by Australian governments’

Anne McKenzie, Janet Wale, Kathie McLure, Ian Hill, Hilary Rumley, Margaret Colbung, Barbara Daniels, Lorraine Powell and Beatriz Cuesta-Briand

Consumer and Community Advisory Council, School of Population Health, University of Western Australia

It is a sad day when Australian researchers talk about suppression of scientific studies and their findings. Yet we were dismayed and shocked that the article by Yazahmeidi and Holman1 says just that.

As Australian citizens we expect the best in health care and disease prevention. We are constantly being told Australia has a thriving economy, access to good education and abundant job opportunities. It seems the country that has thrived on the free spirit is lost and fear and cynicism have taken over. Why do we have to hide the results and hamper the work of our university-based health researchers?

Most of the research that is conducted is publicly funded and, as such, belongs to the community. With population health and health system studies, the health details that are being recorded and reported on is consumers’ information. It seems logical that consumers and the community should not only have access to research findings, but that the information should not be altered in any way.

The basis of ethical research is the ‘uncertainty principle’, that there is uncertainty about the answer to the research question, and that the research is for the public good. You have to know the issues before you can find the best way to address them. Where does this leave consumers if the research cannot be carried out in a meaningful way or results are not published that truly represent the research findings? What good is a disease or other type of database if the information cannot be used appropriately to reduce uncertainty and to identify objectively the true state of affairs?

We live in a world where the International Committee of Medical Journal Editors refuses to publish papers reporting on clinical trials without registration of the trials on a publicly available database. The World Health Organization, of which Australia is a member State, supports the registration of trials through its WHO International Clinical Trials Registry Platform. This is aimed at developing greater public trust in global health research by promoting transparency and accountability for clinical trials registration and reporting.2 Similarly, researchers and their institutions should have an ethical obligation to make sure that all results of public health research are publicly available in a way that does not distort the truth. If all universities are required to observe this principle, it will be much more difficult for government agencies to become involved in research in a way that leads to reported results being sanitised, or never reported at all, to suit the government of the day.

We all exclaim how outrageous it is when the pharmaceutical industry fails to fully disclose all research on drugs or their side effects. This paper tells us we in Australia should be expressing even greater outrage over being given a distorted picture about our health and our health care system.

References

Correspondence to: Ms Anne McKenzie, Consumer and Community Advisory Council, University of Western Australia School of Population Health, c/- Clifton Street Campus M431, Nedlands, Western Australia 6009.
Fax: (08) 6488 1188; e-mail: anne.mckenzie@uwa.edu.au