

**Submission
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THE PROMOTION OF FALSE OR MISLEADING HEALTH-RELATED INFORMATION OR PRACTICES

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Carers NSW response to the Inquiry into the Promotion of False or Misleading Health-Related Information or Practices.

Carers NSW would like to thank the Committee on the Health Care Complaints Commission for the opportunity to respond to this Inquiry. Our response will highlight the responsibility of the NSW Government and the Health Care Complaints Commission to clearly communicate evidence-based health-related information to consumers and carers in order to counter the promotion of false or misleading health-related information and practice.

Carers and false or misleading health-related information and practice.

Carers are the main providers of care in the community, and have been described as the “invisible health workforce” in acknowledgement of this critical role.¹ Carers act as enablers of health care treatment, and support consumers to make decisions about medical treatments. It is therefore essential that carers are equipped with accurate information from reliable sources, so that they can best support their loved one’s health

Carers role in health-related decision making can be stressful, particularly when they are not given clear and adequate information from health care professionals. For example, many carers experience uncertainty about tasks relating to managing their care-recipient’s medicines.² Carers are likely to be monitoring the care recipient’s use of medication and its effects, and they use this knowledge and experience to negotiate with prescribers, pharmacists, nurses and the person for whom they care. However privacy and confidentiality can be used to exclude carers from gaining the information which is necessary to undertake their caring role.³

Carers who do not receive clear and adequate information from health care professionals may seek out alternative sources of information and treatment which are readily accessible, such as online material. Some of this material will contravene accepted medical practice, and could have a potentially detrimental effect on carers ability to maintain their own health, or the health of the person they care for.

Consumers and carers who have low levels of health literacy are likely to be particularly vulnerable to the promotion of false or misleading information and practice. Lower levels of individual health literacy have been found to be associated with poorer ability to interpret health messages, lower use of some medical treatments (including influenza vaccine) poorer knowledge among consumers of their own disease or condition and poorer overall health status among older people.⁴

The Australian Commission on Safety and Quality in Health Care identified that low health literacy was especially an issue for Australia's disadvantaged or vulnerable groups, including those born overseas, and those who are unemployed or not in the labour force.⁵ The Commission reported that almost half (47%) of employed people have an adequate level of health literacy, significantly higher than the proportion of people with adequate health literacy who are unemployed (25%) or not in the labour force (25%).⁶ Carers are more likely to not be in the labour force (41%) than non-carers (32%).⁷ An even larger proportion – the majority – of primary carers (58%) were not in the labour force.⁸ Therefore many carers, including those from culturally and linguistically diverse backgrounds, may be more likely to experience difficulties in interpreting and utilising health-related information.

Promoting evidence based health information and practice

Carers NSW suggests that efforts towards addressing the promotion of false or misleading information or practice should be directed towards empowering health consumers and carers with the information and skills necessary to make the best decisions about their health and that of their loved ones.

Carers NSW notes that in May 2013, the *Health Legislation Amendment Bill 2013* came into force which gave the Health Care Complaints Commission (HCCC) an 'own motion' power to initiate a complaint where there are concerns for public health and safety. Carers NSW believes that this amendment will improve the HCCC's capacity to address the promotion of misleading information and practice. Carers NSW believes it may also be appropriate for the HCCC to issue public statements about any individual or organisation promoting false or misleading health information, if it poses a significant threat to public safety. Carers NSW suggests that these statements should include, or directly refer the public to reputable sources of information on the subject.

Carers NSW emphasises that in order to embed health literacy into our health system the NSW Government must communicate effectively and provide consistent health-related messages to the public which are accessible to diverse groups. Whilst it is beyond the capacity of the HCCC to communicate comprehensive health-related information, we believe the HCCC has the capacity to collaborate with agencies within the NSW Ministry of Health to identify harmful messages and practices which are being promoted in the community, and counter these messages with accurate information and advice.

Conclusion

Carers NSW thanks the Joint Parliamentary Committee on the Health Care Complaints Commission for the opportunity to provide comment on this issue

For further information regarding this submission, please contact Carolina Simpson, Policy and Development Officer, on 9280 4744 or carolinas@carersnsw.org.au.

Yours sincerely,

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¹ National Health and Hospital Reform Commission, A Healthier Future for all Australians – Final Report of the National Health and Hospitals Reform Commission, 2009.

² S R Carter et. al. 'The willingness of informal caregiver to assist their care-recipient to use Home medicines Review', Health Expectations, 2013.

³ National Mental Health Consumer & Carer Forum, Privacy, Confidentiality and Information Sharing- Consumers, Carers and Clinicians, Canberra, 2011.

⁴ Australian Commission on Safety and Quality in Health Care. Consumers, the health system and health literacy: Taking action to improve safety and quality. Consultation Paper. Sydney: ACSQHC, 2013.

⁵ *ibid.*

⁶ *ibid.*

⁷ Australian Bureau of Statistics, Survey of Disability, Ageing and Carers 2009, NSW tables, Table 31

⁸ *ibid.*