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Ms Debra Monk Director, Compliance Medicines Australia Level 1, 16 Napier Close Deakin ACT 2600 deborah.monk@medicinesaustralia.com.au CodeHelpdesk@medicinesaustralia.com.au

Dear Ms Monk

Proposed amendments to the Medicines Australia Code of Conduct

Thank you for the opportunity to attend your stakeholder forum in Sydney on Monday 28 April 2014. We do appreciate the several consultations Medicines Australia has provided for consumer stakeholders.

Cancer Voices Australia remains disappointed that the proposed amendments to the Medicines Australia Code of Conduct will not at all provide cancer patients and their families with transparency around sponsorship and fees paid to health care practitioners ("practitioners").

We consider what you are proposing is insufficient. It needs to be recognised that, in our society, gifts are seen, and usually designed, to influence people. Relying on a practitioner to consent will defeat the purpose of the changes to the Code. There is no incentive for a practitioner to consent. While you say you will monitor the number of practitioners who consent, this will just mean a further delay while we see if this "model" works before further changes are made to give patients information which really they should be entitled to know now.

As a number of people advocated at the forum, including CVA, there is a simple way to achieve what you say you want using the same model you have developed – members of Medicines Australia agree they will not provide sponsorship or gifts to a practitioner unless consent is given to publicly disclose the information. While it is true that consent may later be withdrawn by a practitioner, we strongly believe that if you are serious about providing such information to patients, the starting/default position must be disclosure.

We also consider the delay in provision of information you propose to be so great as to render the information essentially useless to patients. We understand of course there would need to be an initial period to allow practitioners and companies to set up the necessary systems to ensure disclosure was accurate. However beyond the initial set up, it should be possible to provide timely information to the public. Your current proposal sees delays of up to 10 months between receipt of the gift by a practitioner and notification. This is not acceptable and frankly such a delay means the information will be of limited, if any at all, use to patients. We draw your attention to, for example, the Parliamentary Register of Pecuniary Interests which requires Members and Senators to disclose gifts etc within 28 days of receipt.

We are also concerned about the method of disclosure. From a patient's perspective, we will need to search each company individually to see (10 months later) any activity relating to our practitioner (assuming they have provided consent). We strongly recommend a central database be developed as a priority – one which can be searched by both drug and practitioner name. Until that can be developed at the very least companies should have reports which can be similarly searched. It is also important that the information remains available for longer than the two years you have proposed. We think five years is a period which provides a sufficient balance.

We are also concerned that your proposal relates to sponsorship or gifts given to individual practitioners only and not, for example, sponsorship or gifts given to a small practice. This remains an obvious way around your "regime".

We are very disappointed with the proposal as it currently stands and do not think such tokenism advances transparency for patients at all. The upshot of the current proposal is that, from a patient's perspective, we will be able to see that our doctor has directly received (ie not through their practice etc) a benefit from a pharmaceutical company regarding the new drug she/he put you on, if your doctor consents to it being made public, about 12 months later. Such limited information, provided after such a delay, is hardly worth the effort and expense of bringing in a new "system".

We would be happy to discuss this further but without any amendments we will be submitting to the ACCC that the proposed amendments provide no additional transparency for the patient community, in the terms outlined above. The contact for this matter is Bridget Whelan (info@cancervoices.org.au).

Yours sincerely

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Sally Crossing AM Executive Committee

7 May 2014

Cancer Voices Australia is the independent, 100% volunteer voice of people affected by cancer, working to improve the cancer experience for Australians, their families and friends. We are active in the areas around diagnosis, information, treatment, research, support, care, survivorship and policy. To achieve this we work with decision-makers, ensuring the patient perspective is heard.

Cancer Voices has led the cancer consumer movement in Australia since 2000. The CVA network works together on national issues identified as important by their members, with consumers working to help others affected by cancer.

