Cancer Voices Australia

PO Box 5016 Greenwich NSW 2065

phone: 0415785814

web: www.cancervoicesaustralia.org
email: info@cancervoicesaustralia.org



Review of Pharmacy Remuneration and Regulation 2016 Cancer Voices Australia (CVA) Submission

Cancer Voices Australia (CVA) thanks the Review of Pharmacy Remuneration and Regulation for inviting us to make a submission on this topic which is so important to many Australian health consumers.

CVA has been interviewed by the Review Panel and participated in teleconferences discussion with the Consumers Health Forum of Australia, of which we are a long standing member and supporter.

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 facilitates the Australian Cancer Consumer Network of 30 consumer related groups, and has led the cancer consumer movement in Australia since 2000.

Cancer Voices commends the Discussion Paper and the points it raised for comment, and has provided comments on most questions via the interview process. However, as consumers of health services, including medicines, as well as being part of the tax-paying community, the cancer consumer advocacy movement has some concerns which we particularly wish to draw to your attention. A priority for us is the ability to use medicines in a safe and effective manner, which relies on having information about them. Under the present system safe and effective use is in doubt.

The concerns are:

- 1. Seventy per cent (70%) of Australian health consumers lack of information printed about prescription drugs (Hamrosi,KK, Aslani P & Raynor Health Expectations (2014)
- 2. Lack of accountability of expenditure through the Community Pharmacy Agreements (CPA), despite the 6th CPA "pot" having reached the dizzying height of a total \$19 billion over 5 years to 2020.
- 3. Responsibility for the provision of printed consumer medicines information to consumers is very unclear, except for the TGA requirement below. There has been no specific mention that pharmacists should do this since CPA financial incentives to do so lapsed in 2005.

Recommendations:

- Every community and hospital pharmacy be required to display a board listing the services they
 provide, including printed information about prescription drugs they dispense.
- An annual audit be introduced to assess the appropriate and exact expenditure of the current CPA so that taxpayers, consumers and the government know how the \$19 billion is paid to subsidise provision of pharmaceutical services.
- Promulgation and clarification that the "Therapeutic Goods Administration's regulations requires that the CMI be made available to consumers either in the pack or in another manner that will enable the information to be given to the person to whom the medicines are administered or otherwise dispensed". (https://www.tga.gov.au/consumer-medinices-information-cmi). While we agree with the intent of this statement, we do not see it as sufficiently clear as guidance for responsible parties (now at https://wwww.ebs.tga.gov.au).

- All prescription drugs should come with printed information, as a package insert, a printed CMI or both, as occurs in most western countries (UK, Eurozone etc. – inserts mandatory).
- Australia's National Medicines Policy should include guaranteed access to information about drugs prescribed for Australian health consumers.
- Responsibilities regarding exactly who provides the text for CMIs and package inserts (currently medicine product manufacturers according to the TGA) and who provides the information to the actual consumer of the product needs to be clarified.

Discussion

We know the pharmacy sector is highly valued by the community, and rightly so. However, due to the nature of the Pharmacy Guild of Australia (PGA)'s behind closed doors negotiations with government and the reluctance to provide information about drugs directly to consumers to whom they have been prescribed, it is time to seriously review this particular area of pharmacy service in the light of regulation and remuneration.

The pharmaceutical manufacturing industry must also be an integral part of this. While they are required to produce CMIs for every product, they seem to think that parking them on various websites is true "access" for Australian health consumers. Those consumer using the most medicines are the least likely to be able to, or want to hunt for, CMIs on websites. We recommend that the pharma industry also be required to meet the TGA's stated requirements.

We recognise that strengthening this sector of primary care is a Government Priority, and commend it as such. A stronger, more reliable and transparent pharmacy sector can underpin the safe and effective use of medicines for all Australians.

We note that Medicines Australia, the pharmaceutical manufacturing industry body, has taken a keen interest in addressing the lack of printed information provided to health consumers. CVA, CHF and other prominent consumer groups continue to work toward identifying solutions to this major problem.

PGA: It should be noted that the PGA did negotiate direct payment incentives for the production of printed CMIs back in the 3rd CPA (2000-2005). However, the PGA now states (email to CVA dated 1 Sept 2016) that while the program did not make it obligatory to provide a CMI, "pharmacists were encouraged to consider providing them in the following circumstances:

- At the request of the patient
- When the medicine is provided for the first time
- When the dosage form changes (eg from tablet to injection)
- o If there is a significant change in the CMI by the manufacturer
- At the professional judgment of the pharmacist"

Health consumers find these "circumstances" very paternalistic on the whole (except in the cases of dosage form or data change). They appear to abrogate the duty of care that pharmacists should provide printed information, as package insert or in CMI format, with the medicines they dispense. CMI's should always be provided by the pharmacist as part of their duty of care, and as required by the TGA regulations.

These clauses are not based on the best interests of the patient / or consumer of the product regarding the safe and effective use of prescription medicines. They were obviously not made in consultation with a recognised national health consumers group, able to represent the needs and views of the end beneficiaries.

PGA further states "The Guild looks forward to working with Cancer Voices, CHF and other parties to enhance consumer awareness of and access to medicines information, and to also support the provision of CMIs by pharmacists in accordance with the professional standards". The question hanging here is if around only 30% of health consumers receive CMIs, what can those professional standards be? This needs real clarification. Just what these are is not clear to any of the parties. We suggest they are made clear in an addendum to the 6CPA, and by the TGA, on publicly viewable boards in each pharmacy, especially as they relate to CMI provision.

Improving the format of printed CMIs

Further we recommend that the Review should consider recommending that the format and content of CMIs should be fully revamped. They are currently many pages long, unattractively presented and full of repetitious information. A major omission is that the long list of possible side effects gives no indication as to how common or how severe these might be – essential info for the health consumers – eg "these side effects are frequently experienced (in more than 30% of people) but serious adverse effects in only 20%. The following are rare and experienced by less than 5% of people". We need to know this kind of detail to manage our conditions and health.

A single page format was developed by Aslani et al in 2012, to address most of these problems. We recommend it being used as a template for all new or updated CMIs.

Cancer Voices thanks the Government for the opportunity to offer a Submission to the Review of Pharmacy Remuneration and Regulation and trust our consumer view comments will be valued.

Yours sincerely

Sally Crossing AM

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Convenor

22 September 2016

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